

Profiles of Older Wisconsin Residents

**A Summary of Statewide Survey Data
from 2001–2002**

**Wisconsin Department of Health and Family Services
Division of Disability and Elder Services**

November, 2004

Foreword

The Department of Health and Family Services conducts a survey of Wisconsin's older population each decade. This report summarizes the information collected in the 2001-2002 Survey of Older Wisconsin Residents. This publication was prepared by the Department of Health and Family Services in the Division of Disability and Elder Services, Bureau of Aging and Long Term Care Resources.

The material in this report was compiled by Cindy Ofstead, Ph.D., in the Long Term Support Section of the Bureau of Aging and Long Term Care Resources. Florence Rosner edited the text. Donna McDowell, Director, Bureau of Aging and Long Term Care Resources, and Janice Smith, Chief, Long Term Support Section, supervised the project and provided draft review.

Comments, suggestions, and requests for further information may be addressed to:

Cindy Ofstead
Bureau of Aging and Long Term Care Resources
Division of Disability and Elder Services
P.O. Box 7850
1 West Wilson Street, Room 450
Madison, Wisconsin 53707-7850
Telephone: (608) 267-3202
E-mail: ofstecm@dhfs.state.wi.us

Suggested citation:

Wisconsin Department of Health and Family Services, Division of Disability and Elder Services, Bureau of Aging and Long Term Care Resources, Profiles of Older Wisconsin Residents: A Summary of Statewide Survey Data (PDE-3197, 11/2004). November, 2004.

Table of Contents

I. Foreword

II. Executive Summary

III. Survey Background and Methods

IV. Demographic Overview of Participants

- A. The Basics: Age, sex, and race
- B. Marital status
- C. Living arrangements
- D. Rural and urban residence
- E. Education
- F. Employment
- G. Income
- H. Changes ahead: Projections for the older population

V. Health Status and Health Care Utilization

- A. General health and perceived health status
- B. Exercise
- C. Falls
- D. Health care access and insurance coverage
- E. Insurance and prescription drug costs

VI. Economic Well-Being and Preparedness

- A. Income
- B. Home ownership
- C. Assets
- D. Pensions
- E. Work and retirement plans
- F. Planning and the future

VII. Current Housing and Residential Options

- A. Current residence
- B. Changing circumstances
- C. Individual characteristics affect responses
- D. What do older people look for in Assisted Living?
- E. Comparing 2002 choices to 1986 survey results

VIII. Getting Help: Connections to People and Programs

- A. Checking in
- B. Current forms and sources of help
- C. Getting more information and help
- D. Program familiarity
- E. Transportation services

IX. Older Caregivers: Helping Others

- A. Helping co-residents
- B. Helping people living elsewhere
- C. Respondents whose sons or daughters have disabilities

X. Summary and Discussion

Appendix: Profiles of Older Wisconsin Residents Survey Questions

Executive Summary

From October, 2001 through July, 2002 the Wisconsin Department of Health and Family Services Bureau of Aging and Long Term Care Resources conducted a survey of older people in Wisconsin. This random-sample telephone survey by the Wisconsin Department of Health and Family Services collected information from 1,458 people age 65 and older. Survey respondents reside in all parts of Wisconsin, and their demographic characteristics closely resemble those of Wisconsin's older population as a whole. Data from this survey can help us understand and plan for the needs of our rapidly expanding older population. This Executive Summary highlights key findings from each of the survey's topic areas.

Demographic Overview: With a few exceptions, respondents reflected the demographic composition of Wisconsin's older population as a whole:

- Their median age was 73 years.
- 60 percent were women.
- 97 percent reported their race as white.
- About half were married, and a little less than half lived alone (a smaller share – 31 percent - of the state's total population of older people live alone).
- About three in four lived in towns or cities, and the rest in rural areas.
- Respondents reported somewhat higher educational attainment than the state's older population, with 78 percent reporting that they finished high school (compared to 67 percent of the entire older population).
- 79 percent were retired from paid employment; 9 percent were employed for pay.

Health Status: As in most health surveys nationwide, a large majority of survey respondents said they were in excellent or good health. However, as other surveys confirm, older people have a number of health concerns, including specific conditions as well access to care, health insurance coverage, and the cost of prescription drugs.

- 76 percent report being in excellent or good health, although 17 percent said illness or health problems limited their activities during the previous month.
- 41 percent reported a serious health problem such as heart disease, diabetes, cancer, or high blood pressure.
- 10 percent reported a health problem serious enough to limit their ability to care for themselves or carry out regular household activities.
- 12 percent reported blurred or failing vision.
- 32 percent reported hearing problems or hearing loss.
- 90 percent provided an example of a form of exercise they did regularly
- 19 percent had fallen to the floor or ground in the past 12 months, with 26 percent of falls resulting in an injury serious enough to limit their activity for a week or more.
- Falls were associated with activity limitations, dizziness or poor balance, numb or weak legs, medications causing drowsiness, memory problems, and vision problems.
- 76 percent had seen a health care provider in the past 12 months
- 9 percent reported problems getting medical, mental health, or dental care they needed
- 89 percent had some insurance coverage beyond Medicare

Economic Well-Being and Preparedness: Social Security and pensions provide the primary sources of income, and most people say their income meets their basic needs.

- 58 percent named Social Security as their main source of income.
- 22 percent named pensions as their main source of income.
- Of the 84 percent of respondents who provided an annual income amount, about one in four reported incomes below 1.5 times the poverty level
- 53 percent said their incomes met their needs very well, and 38 percent said somewhat well.
- 99 percent said they generally had resources to eat a balanced meal.
- 84 percent were homeowners (with or without a mortgage)
- 87 percent of homeowners and 95 percent of renters reported homes in good repair.
- 24 percent reported assets (not including the value of a home) of less than \$12,000
- 44 percent reported assets of \$12,000 to \$100,000; and 32 percent reported \$100,000 or more.
- 46 percent were receiving a pension from a current or former job, with men much more likely to have pension income.
- Nine percent work for pay; 41 percent of these work full-time, year-round.
- An additional 25 percent had returned to paid work at least once since retiring.
- 60 percent said they had executed a Power of Attorney for Health Care, and 14 percent had a Living Will
- 64 percent had executed a Durable Power of Attorney for the management of finances and property
- 61 percent said they had discussed wishes for their futures with family or friends
- 96 percent said their family and friends understood and respected their wishes regarding future health decisions and care they might need.

Current Housing and Residential Options: Respondents, most of whom were living in single-family homes they owned, were asked about their residential options and preferences if faced with significant physical or health challenges in the future.

- 84 percent were currently living in homes they owned; 16 percent rented their homes.
- 74 percent lived in single-family dwellings, 21 percent in apartments or condominiums
- Of those in multiple-unit dwellings, 39 percent were in buildings specifically for older people; and of those, 40 percent had access to nursing or personal care services.
- 35 percent of renters lived in a low-income or publicly-subsidized dwelling.
- 56 percent would choose to continue living in their current homes if they became unable to do routine household tasks or prepare meals, but most said they would change residences if faced with more challenging changes in their health.
- Among those who would move from a current home, most said they would choose a nursing home or assisted living residence.
- 10 percent or fewer said they would move in with a relative or friend under any circumstance.
- Being married, being younger (under 75), and having more income and assets significantly increased the likelihood of choosing to stay at home.
- Of those who said they would choose an assisted living residence, 64 percent preferred to have their own separate unit in an apartment building, as opposed to sharing living quarters.

- 77 percent prefer a private assisted living bedroom or to live alone, if not with a spouse or relative.
- Most (76 percent) percent said they preferred a mid-sized assisted living building (five to 50 residents).
- Responses to these questions differed in noteworthy ways from similar survey questions asked in 1986.

Getting Help: Connections to People and Programs: Most older people reported regular contact with others and said they could count on help from informal sources for a week or more if they needed it, although fewer than half said they could rely on that help indefinitely.

- Of those living alone, 80 percent said someone checks in with them regularly.
- Respondents' children were the most frequent "check-in" contacts (53 percent), followed by neighbors (24 percent) and friends (15 percent).
- Women and the oldest respondents are more likely to report regular check-ins.
- 89 percent said someone would help them for a week or more if they needed help due to illness or disability. However, just 49 percent said they could get help for as long as necessary.
- 69 percent said a son or daughter would be the source of this kind of help.
- Just 9 percent said they were getting help currently with food, money, rides, etc.
- When asked where they would turn for more help than friends and family could provide, 38 percent mentioned some kind of social or public service provider; 17 percent mentioned a medical provider; and 13 percent said they didn't know.
- 99 percent had heard of "Meals on Wheels," and more than half had heard of most of the other publicly-funded supportive service programs we asked about. One in four had used at least one program, and of those who had not, 81 percent would consider doing so.

Older Caregivers: Helping Others: About one in three older people are connected to others as caregivers, and a small but significant share bear considerable responsibility for helping a son or daughter with a disability.

- 31 percent of respondents reported at least one kind of caregiver responsibility
- Men and women were equally likely to report being caregivers
- Younger and more educated respondents were more likely to report caregiving
- Care for someone living in the respondent's home usually involves an ill or disabled spouse
- Care for someone living elsewhere often involves a son, daughter, or grandchild.
- Almost 10 percent of those with living children had at least one son or daughter with a disability, and 53 percent of these offspring were 45 years of age or older.
- 23 percent of offspring with disabilities lived with their parents
- 16 percent of parents with disabled sons or daughters provided daily care or supervision.
- 22 percent of those providing care for a disabled son or daughter said no arrangements were in place for their child's care if they became unable to continue.
- 46 percent of those providing care for a disabled son or daughter have other caregiving responsibilities as well.

Profiles of Older Wisconsin Residents

A Summary of Statewide Survey Data from 2001–2002

From October, 2001 through July, 2002 the Wisconsin Department of Health and Family Services Bureau of Aging and Long Term Care Resources conducted a survey of older people in Wisconsin. Focusing on residents age 65 and older, the survey asked questions about health, care-giving, participation in programs, work and retirement, and plans for the future. The survey is one of the Department's tools to learn the major concerns of older persons, and to plan and improve our aging programs and services.

The survey was conducted by telephone calls made through the University of Wisconsin Survey Center with a goal of collecting information from 1,500 persons. In all, 1,560 people who were randomly chosen from among all Wisconsin households with telephones met the eligibility criteria¹ and agreed to participate. Of these, 1,453 individuals provided information about themselves, in conversations that lasted about 26 minutes on average. Overall, the survey's response rate was 64.5 percent.

In addition, 102 eligible individuals were unable to participate in the survey directly² but had a relative, friend, or care worker who could answer a subset of the questions on their behalf. The data reported here include only those who answered the questions themselves.

Survey methods

The survey was conducted using random digit dialing technology, in which randomly-generated telephone numbers are automatically dialed by a computerized telephone system. The sample of households included is a simple random sample, not stratified by geographic region, household size, or any other factor. There is no oversampling of rural households, for example, or of older people from any minority group.

Some of the calls made by this method reached inactive numbers, but when a person answered the phone, a live interviewer asked whether the household included persons age 65 or older. If no one in the household met that criterion, the household was considered ineligible and the call ended. If one household member was age 65 or older, the caller requested an interview with that person. If more than one member was 65 or older, the computerized interview software randomly sampled from among them to choose one person to interview. Once an eligible person was identified and agreed to participate, the interviewer determined whether the individual planned to reside in Wisconsin for at least three months during the coming year. If so, the interview began.

¹ To be eligible, individuals had to be 65 years of age or older, and had to plan to reside in Wisconsin for at least 3 of the coming 12 months.

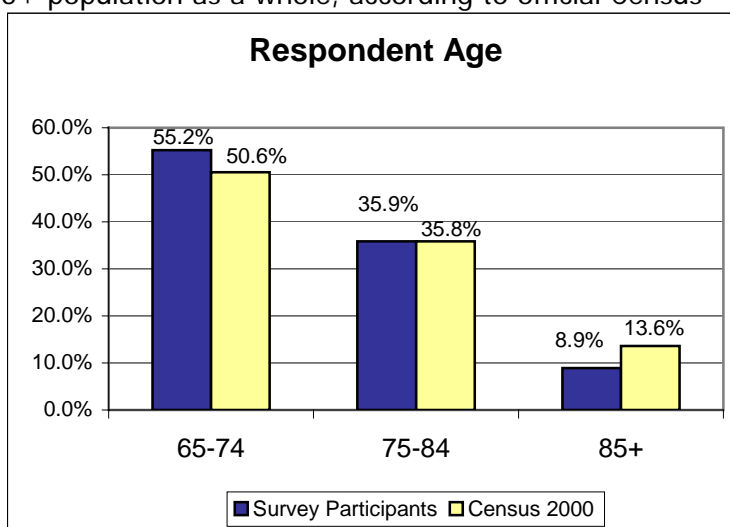
² The most common reasons for inability to participate were hearing impairment (36 percent), advanced illness (18 percent) and physical disability (14 percent). A language barrier was the given reason in eight percent of these cases.

Demographic Overview of Participants

In all, there are 702,553 people age 65 or older in Wisconsin, according to Census 2000³. Of the 2,084,544 households in the state, 479,787 include at least one person in this age group (23 percent of all Wisconsin households). Survey participants were a randomly-selected sample of this population. This section of the report on survey results explores basic demographic information about the participants: their age, sex, marital status, schooling, county residence, living arrangements, and the like. One of the goals of this section is to determine how the survey respondents' basic demographic characteristics compare to Wisconsin's older population as a whole, based on Census 2000 data. This indicates how well the survey responses are likely to reflect and represent all of Wisconsin's older residents statewide.

The Basics: Age, sex, and race

The mean age of those who participated in the survey was about 74 years (the median was 73 years⁴). When tallied in 10-year age groups, the largest share (55 percent) were age 65 to 74, and most of the rest (36 percent) were age 75 to 84. In this regard, survey respondents' ages closely parallel those of Wisconsin's 65+ population as a whole, according to official Census 2000 counts, although a slightly larger share of survey respondents were in the youngest category and a slightly smaller share were in the oldest category, probably because the "oldest old" are more likely to live in nursing homes (which were not included in our sample) and are more likely to have physical, sensory, or cognitive disabilities (such as hearing loss or dementia) that make it difficult to participate in a telephone survey. This illustration compares respondents' ages to those enumerated in the Census.



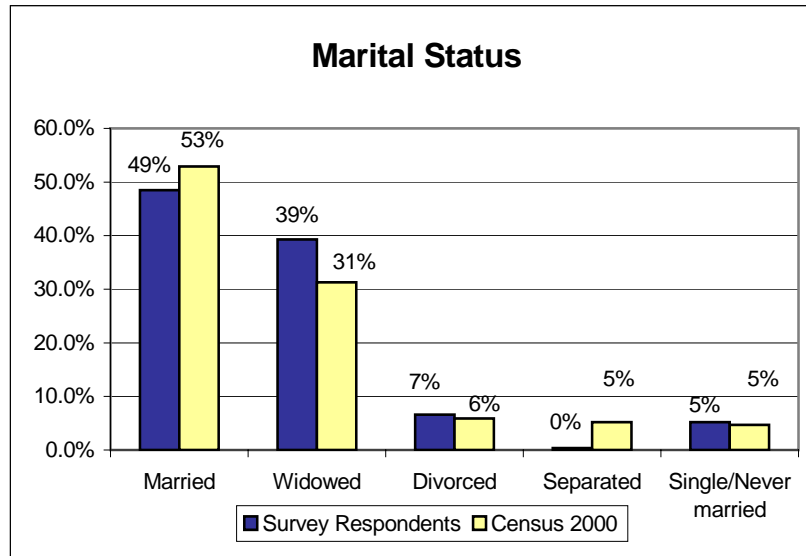
Similarly, survey respondents were male and female at the same rates as Wisconsin's older population as a whole: about 59 percent were women and 41 percent were men. Also like the state's 65+ population, almost all those surveyed reported their race as white: 97 percent of survey respondents, compared to 96 percent of the Census population, said they were white. The second largest race group is made up of African Americans, totaling about one percent of respondents.

³ Population numbers are from U.S. Bureau of the Census, Census 2000, Summary File 1 (100 percent population data). Social and economic information for the state's population as a whole come from Census 2000, Summary File 3 (the Census Bureau's random sample survey taken in conjunction with population counts every 10 years).

⁴ The mean is the mathematical average of all reported values. The median is the "middle" reported value. Half of all responses are greater than the median and half are smaller.

Marital status

There are small differences in the marital status of respondents versus the total older population: 48 percent of respondents are married (compared to 53 percent of the Census 65+ population), 39 percent are widowed (compared to 31 percent), seven percent are divorced (compared to 6 percent), and about five percent of each group are single/never married. In all, 88 percent of respondents have living children. As in the state's older population as a whole, men responding to the survey were much more likely than women to be currently married.



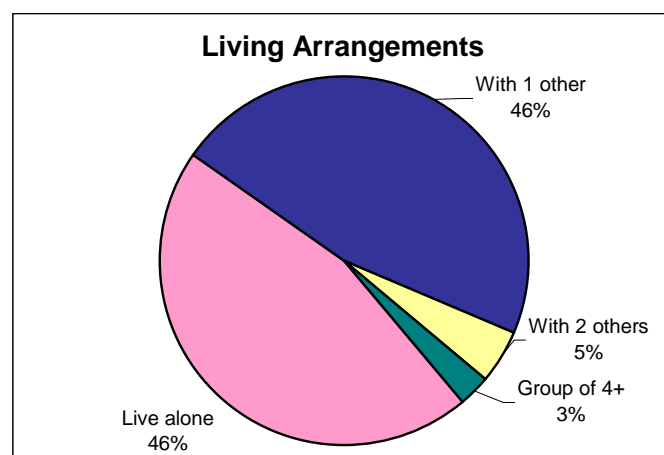
About one-third of women were married (32 percent), compared with almost three quarters of men (72 percent). Conversely, older women surveyed were much more likely to be widowed than their male counterparts: More than half the women were widowed (55 percent), compared to just 16 percent of men.

Significantly, the proportion of respondents who were married declined sharply with age. Of those age 65 to 74, 61 percent were married. However, just 37

percent of respondents age 75 to 84 and just 17 percent of those older than 85 years of age were married.⁵

Living arrangements

In comparison to Census 2000 measures, a relatively large share of the survey sample lived alone. According to the Census, about 31 percent of the state's noninstitutional older population live alone, while about 65 percent live in "family households" containing two or more persons related by blood or marriage. A large majority of survey respondents either lived alone (46 percent) or lived with one other person (47 percent). About five percent lived in three-person households, and the rest lived in larger groups (the largest includes seven persons). Most of the people living in larger groups indicated that household members were economically independent of one another.⁶ The survey did not include those living in nursing homes or other institutional settings, but we know from Census data that 5.4 percent of all



⁵ All of these differences in marital status by sex are statistically significant ($p < .0001$).

⁶ Of the 39 households with four or more members, just 10 were reported to depend upon a shared household income.

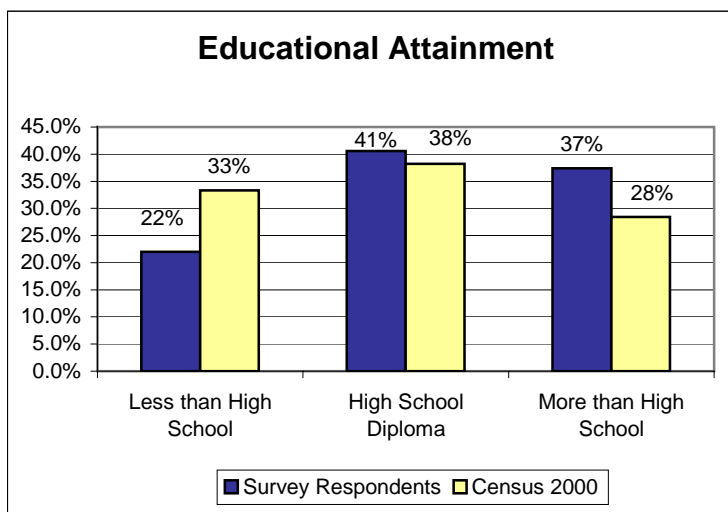
older people in Wisconsin live in nursing homes.⁷

Rural and urban residence

Respondents are distributed among Wisconsin counties in about the same proportions as the population as a whole.⁸ About three quarters live in towns or cities, and the rest in rural areas. According to Census 2000, 68 percent of people of all ages live in urban areas, and 32 percent live in rural areas statewide (Census 2000 has not yet provided this information for older people in particular). More than half of survey respondents (53 percent) had lived at their current residence for more than 20 years, and nearly a quarter (23 percent) had done so for more than 40 years. These figures are very similar to those from the Census, which shows that 51 percent of all older Wisconsin residents have lived in their present homes for more than 20 years.

Educational Attainment

Educational attainment is one of the only areas in which survey respondents differ substantially from Census data on the state's older population. Survey respondents tend to report somewhat more education than the older population as a whole, according to comparisons with Census data. Whereas fully one-third of the state's older population ended their education before getting a high school diploma (or equivalent), just 22 percent of survey respondents reported less than a high school education. And while just 28 percent of the state's older population has some education beyond high school, about 38 percent of the survey respondents reported this much education.



Older respondents were less likely than younger ones to have finished high school.⁹ Eight in ten people age 65 to 74 had done so, but just 60 percent of those age 85 and older had diplomas or Graduate Equivalency Degrees. Similarly, the share of people with education beyond high school decreases with age, from about 56 percent of younger respondents to just six percent of the oldest respondents.

Employment

A large majority of the survey respondents were retired from paid employment (79 percent), although about nine percent said they were currently working for pay. Another seven percent reported that they worked as unpaid homemakers, parents, or grandparents. About two

⁷ The Census does not consider assisted living residences to be institutions. Persons in these settings are counted among those living alone, those living in family households, and those living in other group quarters, depending upon their household compositions.

⁸ The distribution of calls is a result of random sampling. No special effort was made to include calls to all Wisconsin counties.

⁹ Age differences in education are significant at the $p < .05$ level.

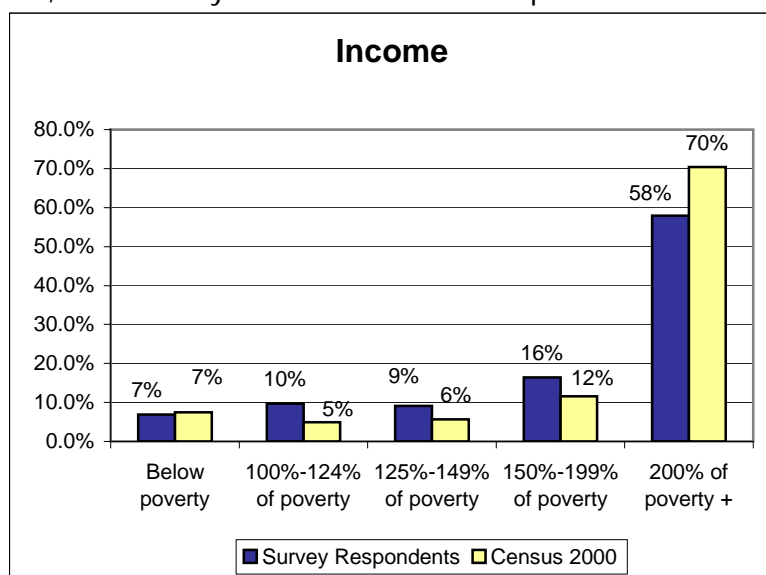
percent were not working due to disability. Less than two percent reported being unemployed, or currently looking for work. Of those who were working for pay, 41 percent worked full time and half worked part-time. The rest (about 9 percent) worked at a seasonal or part-year job.

Male survey respondents were somewhat more likely than women to be currently working for pay (11 percent versus 8 percent), while women were much more likely to report working as unpaid homemakers, parents or grandparents (12 percent compared to less than one percent of men). And not surprisingly, the share of respondents who were currently working at paid jobs declined with age, with no one age 85 or older reporting a current paid job. In contrast, the share of people reporting that they worked as unpaid homemakers, parents, or grandparents held relatively steady across age groups.

The survey's employment numbers are not directly comparable to data from the Census, since the response options differ considerably. However, we do know from the Census that about 13 percent of Wisconsin's older people are employed in the civilian labor force, and that one percent are unemployed (meaning they still consider themselves to be part of the labor force, but do not currently have a paid job). Thus the survey respondents are slightly less likely than the population as a whole to have paid jobs, and slightly more likely to report being unemployed or looking for work.

Income

Income is discussed in detail in a later report section entitled "Economic Well-Being and Preparedness." This section simply compares survey respondents' household incomes to those of older Wisconsin residents responding to the Census. A larger share of survey respondents reported incomes under 200 percent of poverty (42 percent versus about 30 percent in the Census). In fact, more survey than Census income reports fall into each of the lower-income categories,



although slightly fewer survey respondents reported that their incomes were actually below poverty level (6.9 percent compared to 7.4 percent).

While this difference may signal a real divergence between the survey sample and the population as a whole, it is reasonable to surmise that survey incomes are underreported compared to the Census. Although both the telephone survey and the mailed U.S. Census income figures come from self-reports, the swift response time and the

interpersonal nature of the telephone survey environment both increase the chance for error.¹⁰ In addition, about 16 percent of survey respondents did not know their incomes or refused to

¹⁰ On the other hand, many observers feel that the poverty guidelines provided by the Census Bureau underestimate poverty. For example, see "Who's Poor? Don't Ask the Census Bureau." Jared Bernstein, New York Times, 9/26/2003.

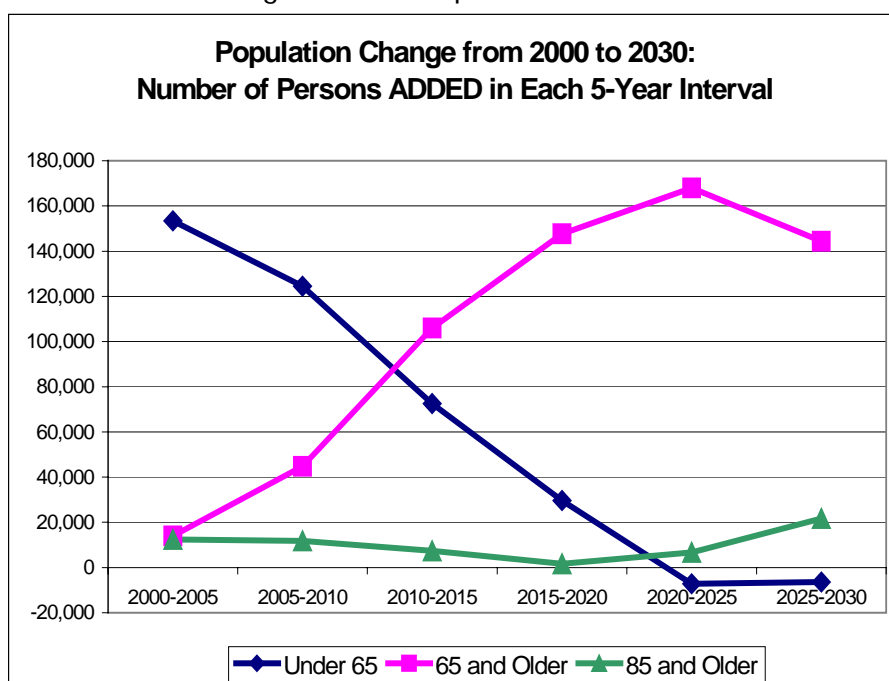
provide income information. “Response bias” may therefore be undermining the reliability of the survey’s income averages, if people with similar characteristics (e.g., high incomes) are more likely than others to refuse to answer certain questions.

Changes ahead: Projections for the older population

Data from this survey can help us understand and plan for the needs of the rapidly expanding older population. Older people make up a growing share of Wisconsin’s total population, and will play an increasingly important role in the state’s social, political, and economic realms for the next 50 years or more. Over the 30-year period between 2000 and 2030, Wisconsin’s total population is expected to grow by almost 19 percent, while the 65+ population increases by almost 89 percent and the 85+ population by 65 percent.¹¹

The 65+ population grew more slowly than the population as a whole between 1990 and 2000 due to the effects of suppressed birth rates during the Great Depression. These effects will

continue for a few more years, but this group will grow at a faster rate than the total population beginning in the 2005-2010 period, and will begin extremely rapid growth in 2011 due to the aging of those born during the Baby Boom that began after World War II. Through about 2030, growth in the 65+ population will be three to five times faster than growth in the population overall. By 2030, one in five Wisconsinites will be 65 or older (Note that this was already true in 2000



for four Wisconsin counties: Burnett, Adams, Vilas, and Iron. These counties are the state’s “oldest,” where median ages of 44 to 46 years contrast with the statewide median of 36 years).

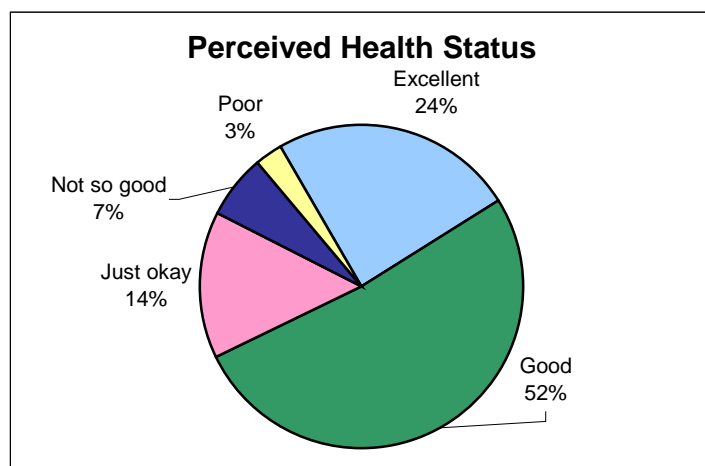
The oldest-old, people 85 and older, currently make up Wisconsin’s fastest-growing age group. This group grew 29 percent between 1990 and 2000, and it will continue to grow faster than the total population or the 65+ population through 2010. However, growth will slacken at that time, due to the effects of suppressed birth rates during the Great Depression (these are the same individuals who entered the 65+ age group during the 1990s). This group will resume its rapid growth in the interval between 2025 and 2030, becoming again the most rapidly growing segment of the population (and that pattern will likely continue through 2049).

¹¹ Population projections are drawn from the Wisconsin Department of Administration, Demographic Services Center, “Population Projections,” April, 2002.

Health Status and Health Care Utilization

General health and perceived health status

In most surveys of health nationwide, a large majority of people say that they are in excellent or good health, and our survey respondents are no exception. A little more than three quarters reported that their health was excellent or good. Leaving out those who had been unable to



carry out their usual activities during the past month because of an illness or health problem, the proportion reporting excellent or good health rises to almost 82 percent. Very few – just under three percent – report being in poor health.

About 17 percent of respondents said that an illness or health problem had limited their usual activities during the past month. A much larger share, almost 41 percent, said that they had been told by a doctor that they had a serious health problem such as asthma,

stroke, heart disease, or cancer. When asked for more details, the largest share said that they had heart disease or had suffered a heart attack. About 14 percent of all respondents indicated this problem, or 208 people in all. The second most common problem reported was diabetes, with 12 percent of respondents reporting it. Other frequently-mentioned health problems include cancer (8 percent), high blood pressure (8 percent), and asthma (5 percent).

Having a serious health problem affects people's reports about their general health, as one might expect. Those reporting a serious health problem were less likely to say they were in excellent or good health – 62 percent did so, compared to 86 percent of those without a serious health problem.

Serious Health Conditions		
	Number	Percent
Heart disease, heart attack	208	14.3%
Diabetes	174	12.0%
Cancer	120	8.3%
High blood pressure	113	7.8%
Asthma	72	5.0%
Arthritis/Joint pain	61	4.2%
Emphysema, lung disease	40	2.8%
Stroke	31	2.1%
Other specified condition	89	6.1%
Other unspecified condition	154	10.6%
Total with any serious condition	594	40.9%
Total responding to questions	1,452	

Of those who were able to respond to the survey themselves,¹² a little more than one in ten reported a health problem serious enough to limit their ability to carry out basic activities, in the realm of physical self-care (dressing, bathing, eating, or using the toilet – three percent in all),

¹² All respondents included in the tables of this report responded to the survey themselves. An additional 102 persons were unable to participate directly but agreed to allow a friend, relative, or caregiver to provide responses to a subset of the survey questions. The occurrence of the kinds of activity limitations addressed here is much greater among the "proxy interview" group.

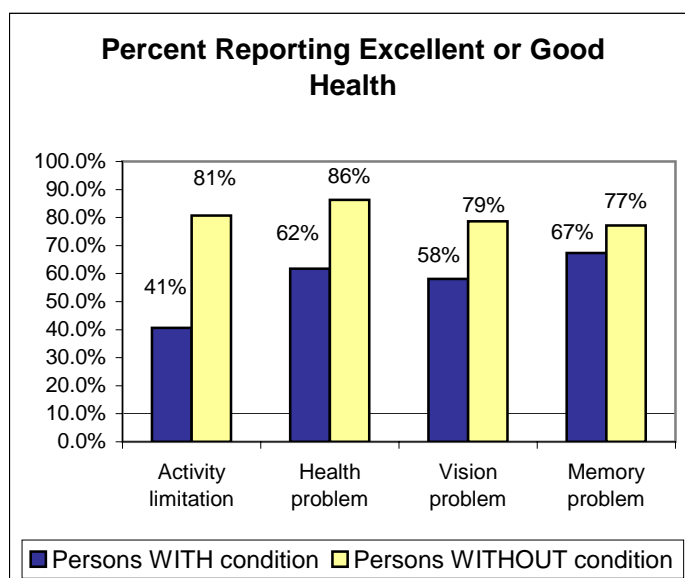
and/or regular household activities (laundry, housework, cooking, or shopping – eight percent in all).

In addition, the survey asked people about vision, hearing, and memory problems. About 12 percent said that they had blurred or failing vision, with an additional five percent indicating vision problems that they believed simply required new glasses. Fewer than two percent reported being legally blind. A much larger share – almost 32 percent - said that they had hearing problems or hearing loss. The prevalence of hearing problems in the population is probably greater than this, however; hearing impairment was the most common reason that willing and eligible people were unable to participate directly in the telephone survey. Of 102 such persons, hearing impairment was the key problem for 37. Similarly, serious memory problems may be underrepresented in our sample since this condition may have impeded participation of some older people in the survey. Of those who did participate, 10 percent said that they had serious memory problems.

With the exception of those with hearing loss, people reporting any of these kinds of health problems tended to have poorer perceived general health than did individuals without serious conditions.

Those with activity limitations of either category (physical self-care or household activities) were the least likely of all to say they are in excellent or good health – 41 percent of them said so, compared with 81 percent of those without such limitations. There was also a very large gap between those with and without at least one doctor-diagnosed serious health problem: 62 percent of the former reported excellent or good health, compared to 86 percent of those with no serious health problem.

Blurred or failing vision is associated with decreased perceived health as well; just 58 percent of those with vision problems said their health was good or excellent, in contrast to 79 percent of those without. And having a serious memory problem is also associated with poorer perceived health, although the gap is smaller: 67 percent of those with memory problems felt excellent or very good, compared with 77 percent of those without. All of these differences are statistically significant.



Exercise

Survey respondents were asked to name specific exercises they did regularly, rather than answering the typical yes/no question "Do you exercise?" A large majority (90 percent) provided at least one example of a type of exercise they did regularly. Seven in ten listed one or more aerobic exercise, such as walking, jogging, biking, swimming, aerobics, dance, or stair climbing. A smaller share (14 percent) listed a strengthening exercise, such as weight lifting, floor exercises, chair exercises, an exercise class or gym attendance, yoga or tai chi. Walking was by far the most frequently-mentioned specific exercise, with 62 percent of all respondents saying they walked regularly. Gardening (13 percent) and biking (10 percent) came in a distant

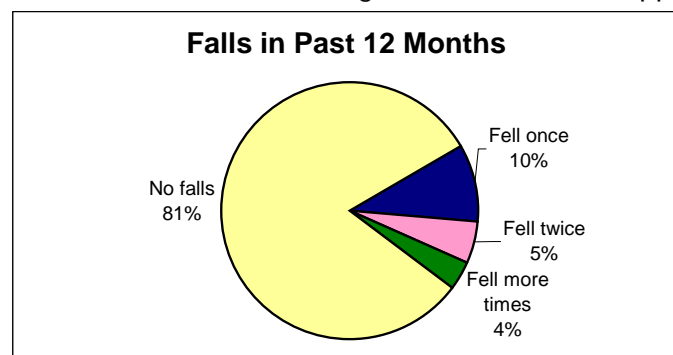
second and third, closely followed by weight training and general housework (10 percent each).

Falls

For older people, falling often causes injury and precipitates other kinds of health problems – particularly problems related to decreased physical activity. According to the Centers for Disease Control's National Center for Injury Prevention and Control, "falls remain the leading cause of both nonfatal and fatal injury among older adults aged 65 years and older in the United States."¹³ Even when they do not result in immediate physical ailment, falls tend to greatly increase older people's insecurity and concern about serious injury, and those who fall are more likely to voluntarily reduce mobility and activity in hopes of avoiding further falls. The result, for many, is growing frailty and isolation and a general decline in health. There is even some evidence that falls are a significant risk factor for nursing home admission. A series of survey questions gauged the prevalence of falls in Wisconsin's older population, where and how people fall, and what kinds of problems or injuries result from falls.

Among survey respondents, almost one in five (19 percent) had fallen to the floor or ground in the past 12 months. About half of these had fallen just once (53 percent), but 28 percent of those who had fallen fell twice and almost 20 percent fell more than twice. Just under half of the falls took place at home (about 47 percent), and a slightly smaller number occurred outdoors (45 percent). Of the rest, almost all took place indoors, away from home.¹⁴

The most common reason given for a fall was tripping, slipping, or stumbling, with about 43



percent of people saying they believe this is what caused at least one of their falls. The second most common cause was slipping on ice, in particular (13 percent). No other single reason was given by more than 10 percent of respondents, but missed steps, dizziness, weakness, and carelessness were the most frequently mentioned other causes (5-6 percent each).

More than one in four people who reported a fall (26 percent) were injured badly enough that it was difficult for them to do regular activities for seven days or more. Of these, 83 percent sought medical treatment. Falling resulted in disability for 17 percent of those who were injured.¹⁵ Most of the specific injuries mentioned were fractures, with six percent reporting hip fractures and 42 percent mentioning some other kind of fracture. Bruises, cuts, and scrapes were mentioned by 28 percent, and general pain and soreness by 14 percent. About 10 percent mentioned sprains.

¹³ "Public Health and Aging: Nonfatal Injuries Among Older Adults Treated in Hospital Emergency Departments, United States, 2001." CDC's Morbidity and Mortality Weekly Review, 52(42):1019-1022 (2003).

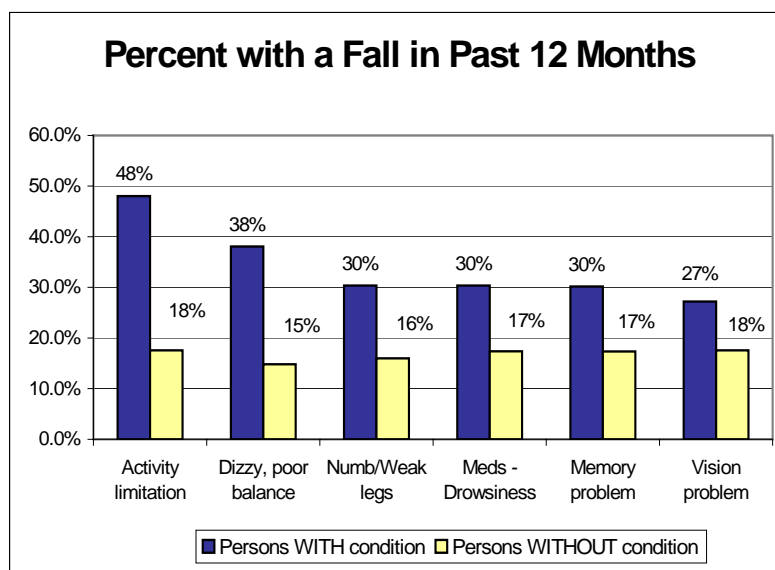
¹⁴ One study of fall risk in community-dwelling older people found that 40 percent fall each year (Hausdorff, J.M. et. al, "Gait variability and fall risk in community-living older adults: a 1-year prospective study." *Archives of Physical Medicine and Rehabilitation* 82:1050-1056, 2001.

¹⁵ "Disability" was not defined for respondents; they were simply asked "Would you say the injury resulted in a disability?"

It is important to note at this point that, with regard to falls and fall-related injuries, the individuals included in our survey are not representative of the population as a whole. Among all older people admitted to hospitals with fall-related injuries in 2000, 46 percent were discharged to skilled nursing facilities; only 25 percent were sent home.¹⁶ Thus those who experienced the worst consequences of falling may not be in the community-dwelling population from which the survey sample was drawn. These survey data on falls and related injuries almost certainly underestimate those events.

Older people's greater likelihood of falling is believed to be linked to a number of underlying health problems, from hearing and vestibular ear problems to conditions like diabetes. The survey asked about a number of specific conditions and symptoms that can increase the risk of falling. Some, like dizziness and problems with balance, may also be indicators of other underlying problems (in this case, with ear or neurological function). About 17 percent of respondents reported dizziness or balance problems. Additionally, as noted above, about 32 percent said they had hearing problems or hearing loss. Although different parts of the inner ear are associated with hearing and balance, both categories of ear function can be jointly affected by infection or injury, so hearing problems may indicate the undiagnosed presence of vestibular problems as well.¹⁷

Eighteen percent reported numbness or weakness in the legs, which can cause falls and also may indicate vascular problems or diabetes. About one in ten said they had a serious memory problem, which can lead to confusion and misapprehension of distances and obstacles, resulting in falls. About eight percent said they take medications that make them drowsy. Under any medical circumstances, drowsiness increases the likelihood of falling. Finally, as noted above, about 16 percent reported some vision problems (though almost one third of those were thought by respondents to be caused by out-of-date eyeglasses). Poor vision, and also use of bifocal corrective lenses, are associated with greater likelihood of falls in the population as a whole.



¹⁶ "Risk Factors Associates with Hospitalization for Unintentional Falls: Wisconsin Hospital Discharge Data for Patients Aged 65 and Over." Guse, Clare E. and Rebecca Porinsky. *Wisconsin Medical Journal* Vol. 102, No. 4 (pp. 37-42), 2003.

¹⁷ *Clinical Neurophysiology of the Vestibular System* by Robert W. Baloh, M.D., and Vicente Honrubia, M.D. (F.A. Davis Company, Philadelphia, 1990, 2nd edition). See also <http://www.vestibular.org/overview.html>.

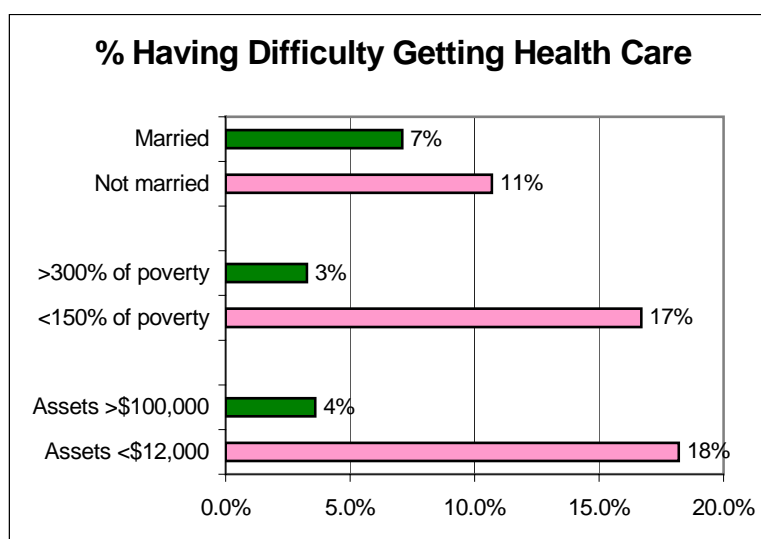
As it turns out, all of these conditions, with the exception of hearing loss, are associated with falling in our survey results.¹⁸ Those with activity limitations are most likely of all to have had a fall in the past 12 months; 48 percent of them had fallen compared to 18 percent of those whose health did not limit their activity. Similarly, those with problems related to dizziness and poor balance were far more likely to have fallen than those without such problems – 38 percent versus 15 percent. Almost one-third of people whose legs felt numb or weak, and the same share of those whose medications made them drowsy, fell during the past year, compared with about half as many of those without such complaints. Memory and vision problems also significantly increased the likelihood of a fall.

Other medical conditions make little difference in the likelihood of falling. Among personal characteristics, only being older (age 75 or older) and being female cause significant (though small) increases in the chances of falling.

Health care access and insurance coverage

Most older Wisconsin residents have seen some kind of health care provider in the past 12 months. Among survey respondents, about three quarters (76 percent) had done so. This figure is lower than expected, based on results of the Wisconsin Family Health Survey (FHS)¹⁹ which show that people age 65 and older are more likely than persons in any other age group to have seen a medical doctor in the past year. According to the FHS, 93 percent of older people have seen a doctor, compared to 85 percent of people under 65. Family Health Survey results also show that those in this age group had an average of five doctor visits during the year, compared to an average of four visits for people under age 65 (respondents were not asked to specify how many times they had seen a health care provider).

The survey asked whether anything “makes it difficult for you to get the medical, mental health, or dental care you need?” Nine percent reported problems, mostly having to do with money (two-thirds of those who had a difficulty), transportation (22 percent), or insurance (16 percent). For the most part, personal characteristics did not significantly affect people’s responses to this question. Women and men, older and younger people, and those with various levels of education all



¹⁸ These variables are generally significantly and positively correlated, although the correlation coefficients are small, probably because the number of cases with each characteristic is relatively small. Significance for these relationships is based on crosstabulations with chi-square statistics.

¹⁹ The Family Health Survey is an ongoing random sample telephone survey of Wisconsin households, conducted by the Wisconsin Department of Health and Family Services Bureau of Health Information (Division of Health Care Finance).

responded similarly.

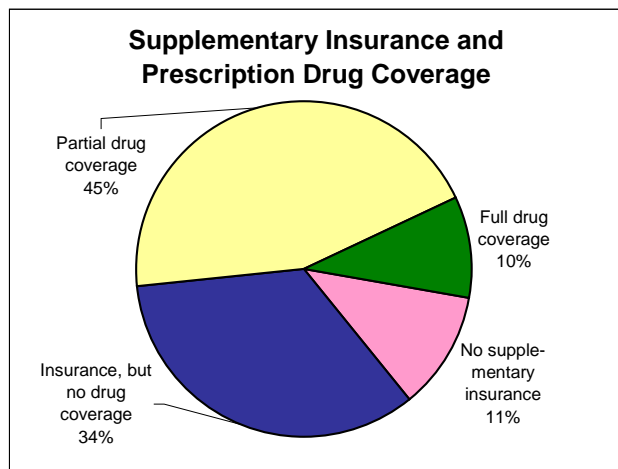
However, unmarried people were significantly more likely to report difficulty, as were those with lower incomes and fewer financial assets. The unmarried were about four percent more likely to have trouble getting care than were married people, while those in the lowest income group are 13 percent more likely than those in the highest income group to have trouble. Similarly, those with the fewest financial assets (less than \$12,000 excluding the value of a home) are 15 percent more likely than the highest-asset group to have problems getting care.

Insurance and prescription drug costs

This survey took place well before the Medicare Modernization Act of 2003, and before the initiation of Wisconsin's prescription drug assistance program, Senior Care, so responses to the insurance questions should be understood in historical context. Answers would be different today, since the realm of insurance and prescription drugs has changed. In mid-2002, most respondents (89 percent) said they had some kind of health insurance besides Medicare, the federal health insurance program for all persons age 65 and older. This additional or supplementary insurance may be a privately purchased health insurance policy, public Medical Assistance, or a special supplementary insurance package, called "Medigap" coverage. Each of these supplements could be important for older people's economic security if they helped pay for some basic medical expenses not covered by Medicare at the time of this survey, such as prescription drug costs.

Survey results show that both personal and economic characteristics make a significant difference in people's likelihood of having insurance other than Medicare. The biggest differences, as one might expect, are based on affluence: 97 percent of those in the highest-income group have additional health insurance, compared to 80 percent of those in the lowest income group. Similarly, 95 percent of those with the most financial assets have additional insurance, compared with 77 percent of those with the fewest. As people get older, they are also less likely to have this kind of coverage: 90 percent of those 65 to 74 have it, but just 81 percent of those age 85 or older do. Ninety-four percent of those with more than a high school

education have additional coverage, compared to 86 percent of those with less formal education. Married people are covered more often than unmarried (91 percent vs. 87 percent). Gender does not significantly affect this kind of insurance coverage.



According to the DHFS Family Health Survey, 82 percent of older people needed or used prescription drugs in the three months prior to their interview in 2002.²⁰ Prescriptions are often a major expense for older people, particularly when they do not have supplementary insurance (beyond Medicare).

²⁰ Family Health Survey, 2002, Wisconsin Department of Health and Family Services, Division of Health Care Financing, Bureau of Health Information. Note that Senior Care, the prescription drug purchase assistance program for qualified Wisconsin residents age 65 and older, was not in place at the time our interviews took place (it was implemented in September, 2002).

This survey shows that only 10 percent of all respondents have full drug coverage, and 45 percent of the full sample have no drug coverage at all. But even those with additional coverage are not always free of drug expenses. For 61 percent of those with some kind of additional insurance, coverage included all or part of the cost of prescription medications; for the other 39 percent, prescriptions were not covered. Half of all respondents reported out-of-pocket prescription expenses or copayments of \$400 or more in the previous 12 months (one in four reported spending less than \$100, and another one in four spent \$1,200 or more). For about one in six (17 percent), the previous year's expenses were unusual and a more typical annual cost would be about \$300, on average (median).²¹

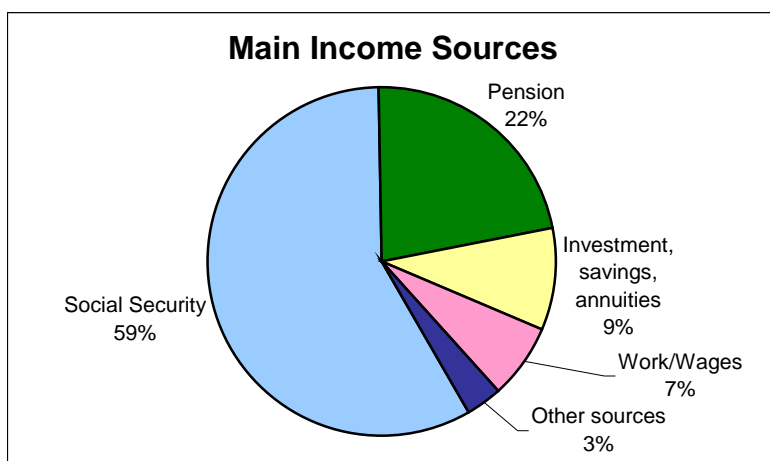
Those with health insurance besides Medicare were significantly more likely to have seen a health care provider in the previous year. About 78 percent of insured respondents saw a provider, while just 63 percent of those without additional insurance did so. The prescription drug costs of those with Medicare only (no supplementary insurance) were higher, as well, averaging \$500 for the previous year (Medicare did not cover medications at the time of the survey).

²¹ Median costs are used here to represent averages, because a small number of respondents had extremely high out-of-pocket drug expenses that distorted the calculated mean. In all, 21 respondents reported expenses of \$5,000 or more. All but three of these had insurance besides Medicare, but only seven had policies that covered part of prescription drug costs. Two had spent \$10,000 and one spent \$13,000 in the past year.

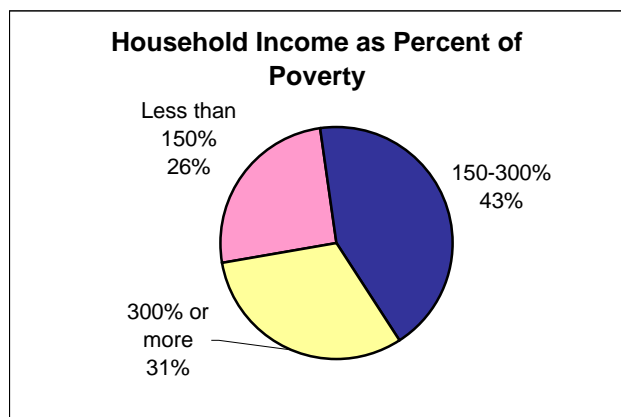
Economic Well-Being and Preparedness

Income

For most of the households whose members responded to our survey, Social Security makes up a very significant share of income. About 58 percent named Social Security as their main income source, and another 19 percent said it was their second major source of income. Pensions are next, with 22 percent naming them first and 20 percent listing them as the second major income source. About nine percent said investments or personal savings were their most important income, and about seven percent depend mainly on wages from current jobs. These last two sources also provided important second incomes for many people: savings and investments for about 14 percent, and wages for another 10 percent. Altogether, these four kinds of income - Social Security, pensions, investments and savings, and wages - make up the primary income source for 96 percent of respondents. The same four sources provide a second major income for about 59 percent of all respondents (or 91 percent of those who said they had a second major source of income).



How much money do these sources provide to the households of older Wisconsin residents? People were asked to indicate their total household incomes by choosing from a set of dollar amount ranges. (e.g., "less than \$25,000; between \$25,000 and \$50,000, or more than \$50,000). The specific ranges listed for each person were generated by the computer to take



into account the number of household members dependent on that income, and the federal poverty level for that household size. This method allowed a calculation of how close each household was to the poverty line.

Poverty level for a household of one in 2000 (the reference year) was \$8,530; and about 52 percent of respondents lived in households of this size. Poverty level for a household of two was \$11,250, and 45 percent of respondents were in two-person

households.²² In all, about one in four respondents had household incomes below 1.5 times the poverty level, or "150 percent of poverty." The largest share (43 percent) had incomes

²² For income purposes, a household is defined as the number of people living together and also sharing a combined income. Some respondents lived with one or more unrelated housemates but were

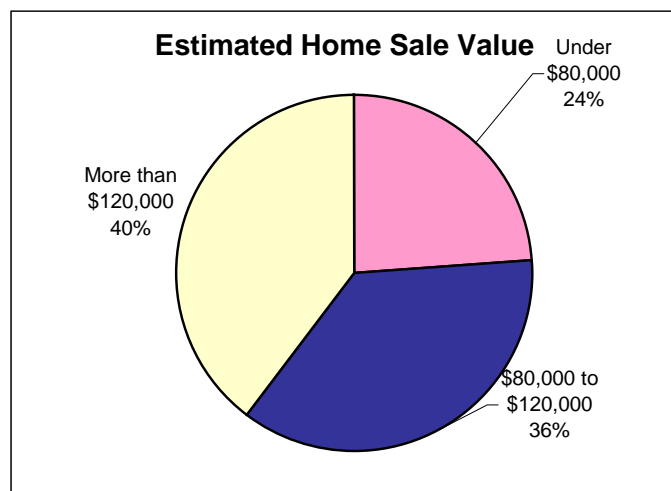
between 1.5 and three times the poverty level, and 31 percent had incomes of three times poverty or more.²³

While a household's relationship to the federal poverty line gives a fairly good sense of how well its members are doing financially, it is also important to know how Wisconsin's older people *feel* about their economic status. When asked how well their current income was meeting their needs, nine out of ten said either "very well" (53 percent) or "somewhat well" (38 percent). Another seven percent said "not very well," and just two percent said "poorly." Almost everyone (99 percent) said that they generally had enough money or Food Stamps to eat a balanced meal.

Home ownership

Home ownership is often a very important component of economic security for older adults. A large majority (84 percent) of survey respondents were living in a home that they owned (with or without a mortgage). Just 16 percent rented their homes. Among homeowners, most (87 percent) reported that their homes were in good repair (an even higher proportion of renters – 95 percent – said this). Somewhat more than half of those who reported needing major home repairs said that they could afford to make the improvements (58 percent), although four in ten said they could not.

Homeowners were asked to estimate the current sale value of their homes. Four out of ten estimated that their homes would sell for more than \$120,000. Another 36 percent thought they could get between \$80,000 and \$120,000, and the smallest share – 24 percent – thought their homes were worth less than \$80,000. These proportions are almost identical to the home value information collected by Census 2000 for Wisconsin homeowners of all ages, indicating that survey respondents' estimates are probably reasonably accurate.²⁴



Assets

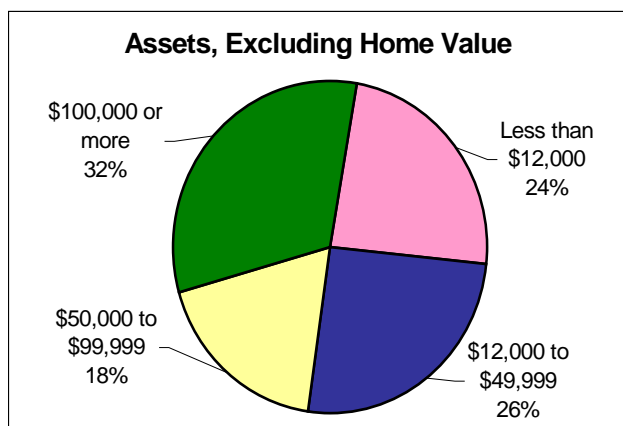
Beyond the value of a home, older adults may have financial assets to provide income and security in later years. Respondents were asked to estimate the total value of their assets,

economically independent of them. Similarly, some individuals and couples had economically independent offspring or others living in their homes.

²³ Note that, as indicated in the introductory section, about 16 percent of survey respondents (233 persons) did not know their incomes or declined to provide income information. "Response bias" may therefore be undermining the reliability of our income averages, if people with similar characteristics (e.g., high incomes) are more likely than others to refuse to answer certain questions.

²⁴ According to Census 2000, Summary File 3, Table HO74, 24 percent of homes are valued at less than \$80,000; 35 percent are valued between \$80,000 and \$125,000; and 42 percent at more than \$125,000 (note that the response categories differ slightly from our survey categories).

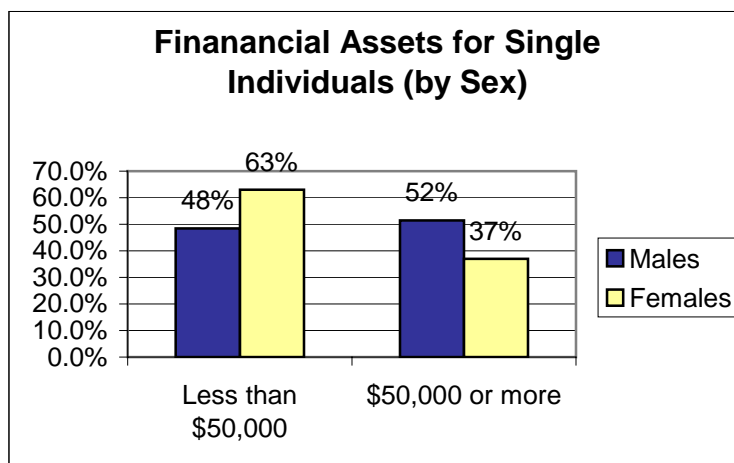
defined as savings, investments, retirement funds, and the cash value of insurance policies (but excluding the value of their home). Like the survey's income question, the assets question was framed as a series of dollar-amount ranges for respondents to choose among.



About one in four respondents reported assets of less than \$12,000. Another one in four had assets totaling between \$12,000 and \$50,000, while 18 percent had saved between \$50,000 and \$100,000. The largest share of respondents, 32 percent, had total assets of \$100,000 or more.²⁵

As one might expect, assets vary significantly among different demographic groups in the survey sample. The oldest respondents (age 85 and over) reported the fewest assets,

having depended upon them for the greatest number of post-retirement years. Married couples reported more assets than those not currently married (including divorced, widowed, separated, and never-married individuals). Those with education beyond high school also had significantly more financial assets than those with a high school diploma or less. And finally, unmarried men had significantly more assets than did unmarried women. Among married individuals, as well, married men tended to report significantly more assets than did married women. This latter difference is difficult to interpret, although it suggests that men's and women's understanding of the financial assets available to their households may differ.



Pensions

As noted above, pensions constitute one of the most important income sources for older Wisconsin residents, with about one in five survey respondents naming them as the primary source of household income. At the time of the survey, 46 percent of respondents were receiving a pension from a current or former job. Another 11 percent, who were not yet retired, said that they would receive a pension when they did retire. Of those still employed, 44 percent expected to receive a pension upon retirement.

The survey asked married and widowed people about the pensions of their spouses, as well. Nearly half (48 percent) of married individuals said that their spouses were currently receiving a pension or would collect one upon retirement. Of respondents with pension-owning spouses, 67 percent said that they, themselves would continue to receive full pension payments (26.5

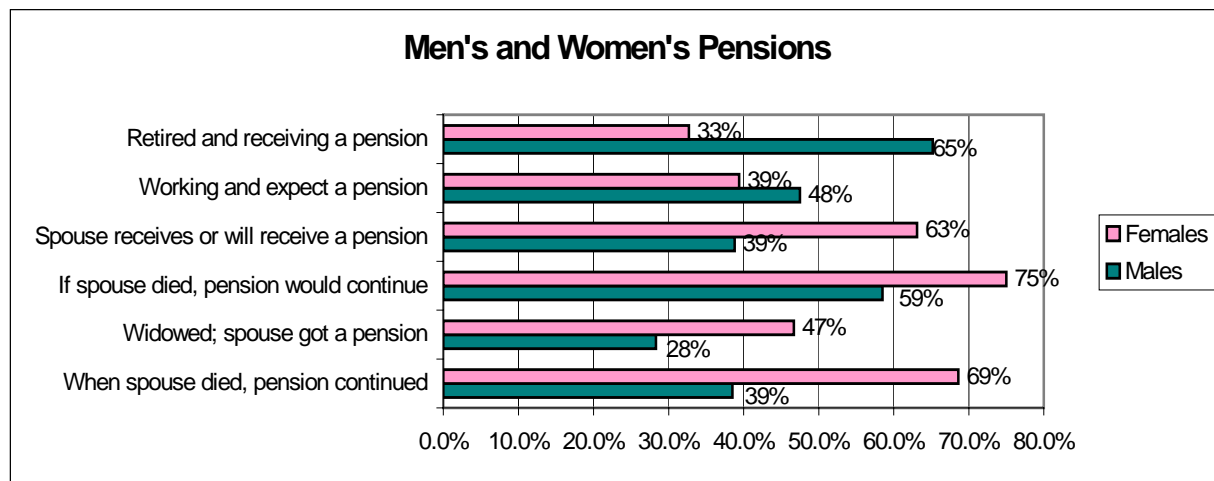
²⁵ About 22 percent of respondents did not know their total asset value or declined to provide information.

percent) or partial payments (40.6 percent) if their spouses were to die first. Among respondents who were already widowed, 44 percent of deceased spouses had received pensions, and 65 percent of those pensions continued to be paid to the widowed respondent in full or in part after the death. The similarity between the expectations of married respondents

Pension Experiences and Expectations		
	Number	Percent
Retired and receiving a pension	648	46.3%
Working and expect a pension	163	43.8%
Spouse receives or will receive a pension	325	48.2%
If spouse died, pension would continue	190	67.1%
Widowed; spouse got a pension	241	43.7%
When spouse died, pension continued	152	65.2%

and the actual experiences of widowed respondents is striking, suggesting that married older people have an accurate understanding of their spouses' pension arrangements.

There are clear gender differences in respondents' reports about pensions. Retired men were much more likely than retired women to be collecting a pension, and working men were more likely than working women to say they expected to do so upon retirement. Conversely, married men were much less likely than married women to report that their spouses were receiving or expected to receive a pension. Further, among the widowed, men were much less likely than women to continue receiving either full or partial pension payments after the earning spouse had died. All of these differences, with the exception of the pension expectations of currently working men and women (a very small number of persons in all), are statistically significant.



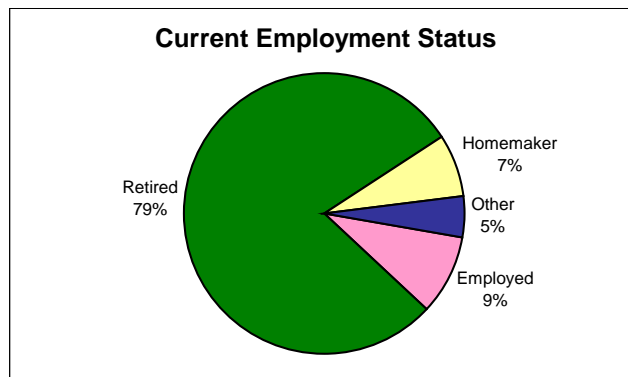
Finally, about five percent of respondents said that either they or their spouses had lost some pension benefits due to a reorganization or merger involving a former employer. Of those who had lost funds, 60 percent had their pension amount reduced and 40 percent had lost all pension benefits.

Work and retirement plans

Paid employment remains important for a substantial number of older people. Nine percent of survey respondents were currently employed in paid jobs. Of these, 41 percent were working full time, exactly half were working part-time, and the other nine percent worked on a seasonal or part-year basis. In addition to these working adults, about one out of four people who were currently retired said that they had returned to work at least once after retiring. Men were significantly more likely to have resumed working after retirement; 31 percent of men and 18

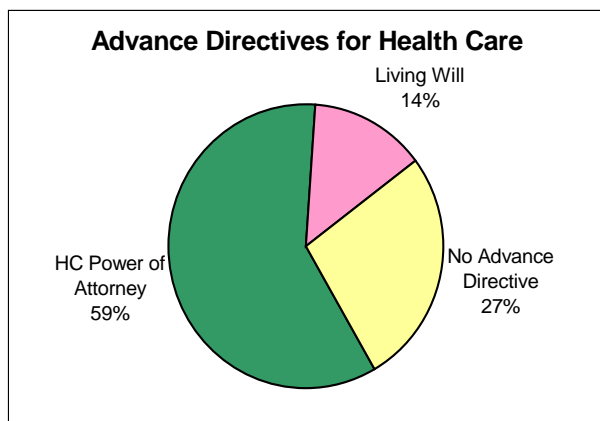
percent of women had done so. Of those who said that they were currently working as homemakers, were disabled, or were otherwise unemployed (but not retired), almost three quarters had held a paid job previously.

Currently-working individuals were asked about their plans for retirement. About 46 percent expected to retire by age 75, but 17 percent planned to wait until they were 75-79 years of age, and another eight percent planned to retire at age 80 or older. Thirty percent said they would “never” retire. There were no significant differences between men’s and women’s plans for retirement.



Planning for the future

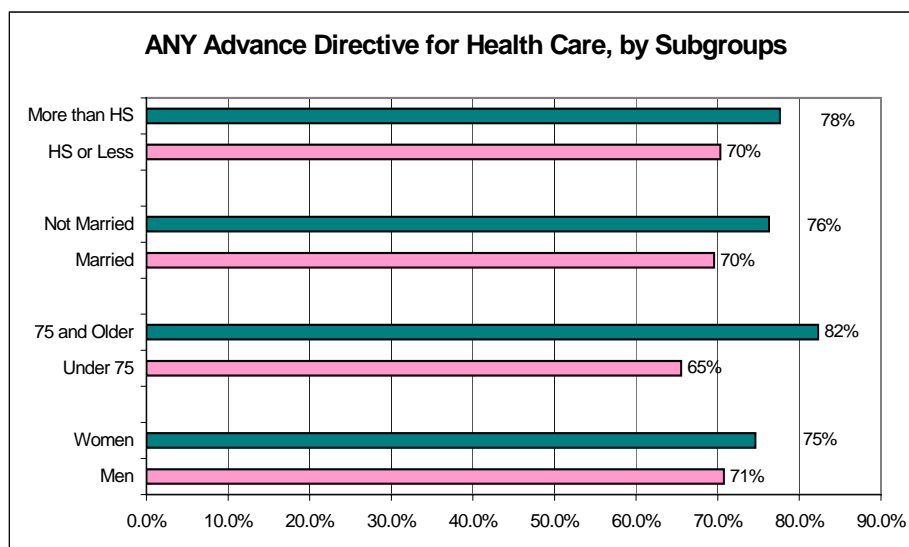
A brief series of survey questions inquired whether and how older people have prepared and communicated their wishes about their future care and economic security. To begin with, the survey asked about some legal documents that record an individual’s intentions in preparation for an eventuality in which he or she becomes unable to make or express decisions.



About six in ten survey respondents said that they had completed and signed a legal document called a Power of Attorney for Health Care, a form of advance directive assigning a third party to make health care decisions in the event that the signatory becomes unable to do so. Of those who said they had not assigned a Power of Attorney for Health Care, about one in three (34 percent, or 14 percent of all respondents) had signed a “Living Will” advising health care professionals about their wishes for end-of-life care. In all, 73 percent of

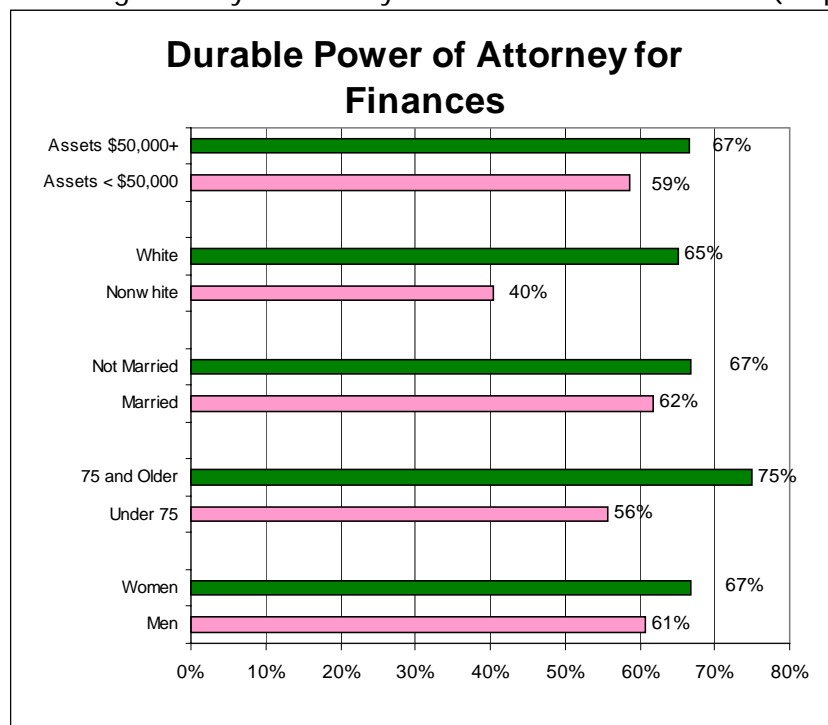
respondents had signed one or the other.

Older respondents (75 or over), those with more education, and those with higher total savings (measured as the sum of all assets excluding the home) were significantly more likely to have completed an advance directives. Married people and nonwhites were significantly less likely than their counterparts to



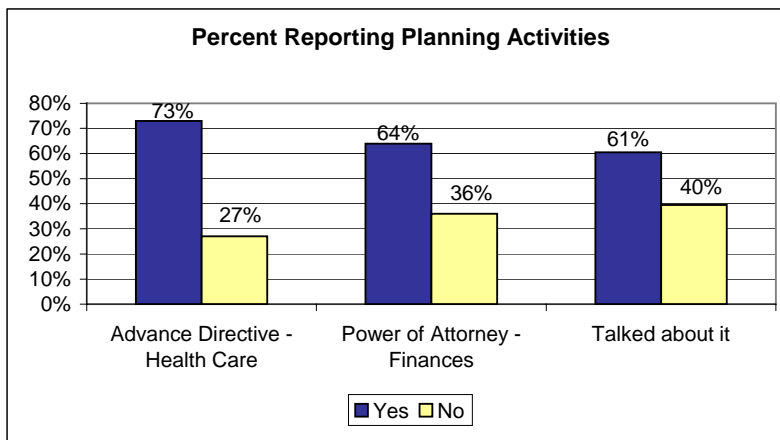
have an advance directive of either kind. While being female, having higher income and a higher home value are all associated with significantly greater likelihood of having executed a power of attorney for health care, none of these factors make a significant difference in the likelihood of having a living will. Interestingly, indicators of health status do not affect people's chances of having an advance directive. Responses do not significantly differ based on general health self-reports, having a chronic health problem, or having limitations in carrying out activities of daily living.

A separate process exists to assign a third party to manage property or finances if a person becomes unable to do so. Among survey respondents, about 64 percent said they had executed a Durable Power of Attorney for the management of finances and assets. Women were significantly more likely than men to have done this (67 percent vs. 61 percent), and the



likelihood of having designated this kind of legal authority increases significantly with age and with accumulated assets. As with the advance health directives, being married and being nonwhite significantly decrease the chance that a person will have designated a durable power of attorney to manage their financial affairs. All together, married people, those under age 75, and racial nonwhites are consistently less likely to have made any of these legal arrangements to formalize their health care or financial wishes in case of eventual incapacity.

The survey also asked whether respondents had taken a more informal approach to preparing for the future by discussing their wishes with friends or family members, particularly regarding the possibility that they would eventually become unable to take care of themselves at home without help. About six in ten said that they had done so (61 percent), with another six percent saying that they had "sort of" discussed this, or talked about it "in general." Women were significantly more likely than men to have had this kind of discussion (70 percent vs. 61 percent), as



were unmarried people (69 percent vs. 64 percent of married people). Regardless of whether or not they had discussed these matters, the overwhelming majority (96 percent) of respondents said that they believed their friends and family members understood and respected their wishes regarding their own future health decisions and care they might need.

Finally, respondents were asked if they had purchased a long-term care or nursing home insurance policy. About 16 percent said they had such a policy. People in higher income groups, those with more assets, more education, and higher home values were significantly more likely to report having long-term care insurance. No other demographic factors made a significant difference in responses to this question, although younger respondents and males were slightly more likely to have insurance than were their counterparts.

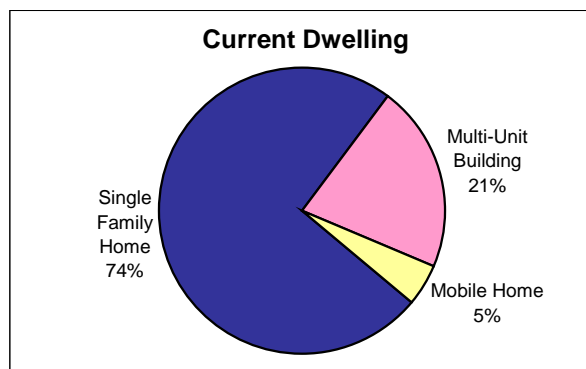
It may be important to consider these reports of insurance coverage in light of other data on long-term care insurance, because questions have been raised about the accuracy of Americans' understanding of their insurance status. An American Association of Retired Persons (AARP) survey of older people nationwide found far more people believed they had long-term care insurance (27 percent of those age 65 and older) than likely do based on estimates from the Health Insurance Association of America (about six percent of adults of all ages). The AARP believes people confuse long-term care insurance with other types of coverage, such as disability insurance or Medicare. AARP has raised concern that people may have an illusory sense of security about their economic future because they falsely believe they are insured for long-term care. The survey sample reported much lower incidence of insurance coverage than did the AARP sample, but the proportion covered may still be exaggerated in these data.

Current Housing and Residential Options

Current residence

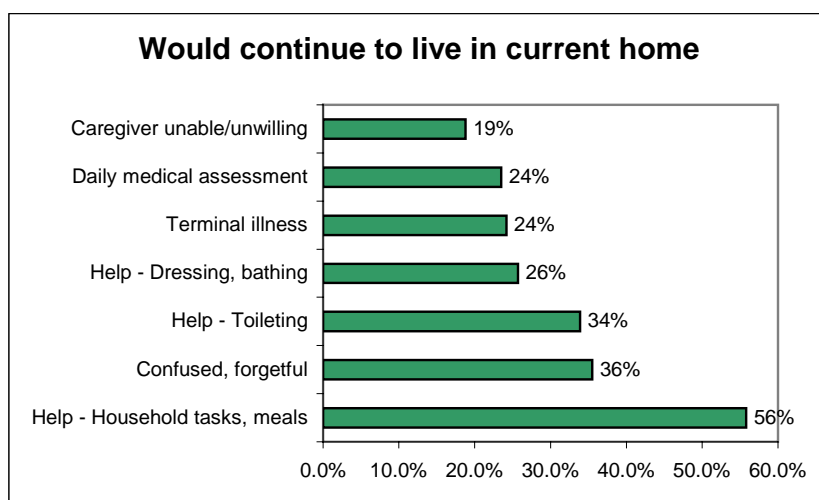
Most survey respondents (84 percent) were residing in homes that they owned (or were buying). Just 16 percent rented their homes. Most lived in single family homes (74 percent), with the rest living in apartments, duplexes, or condominiums (21 percent) or mobile homes (about 5 percent). Of those in multiple-unit dwellings, nearly four in ten (39 percent) were in buildings specifically for older people; and of these, 69 percent were in buildings providing assisted living services. About 40 percent of those in buildings for older people had access to nursing or personal care services there. All together, about 35 percent of renters lived in a low-income or publicly subsidized dwelling.

The survey included a series of questions asking where people would choose to live if their health or care needs changed in specific ways. The goal was to understand both how people view their residential options as they age, and what kinds of changing circumstances are most strongly associated with particular residential choices.



Changing circumstances

A majority of respondents (56 percent) said they would choose to remain where they now live if they became unable to do routine household tasks or prepare meals for themselves. But most indicated that they would change residences if faced with any of the other changing circumstances listed. For instance, about 36 percent say they would stay at home if they were



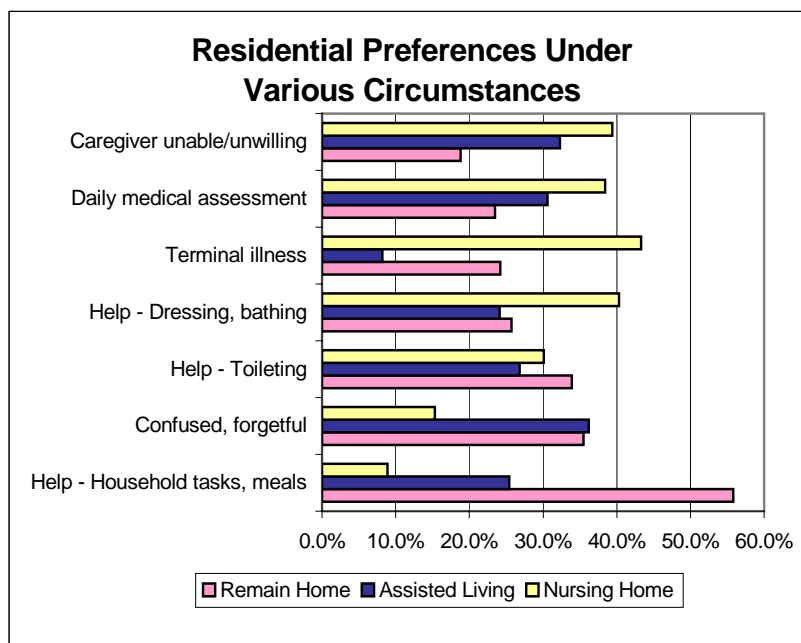
in danger because of confusion or forgetfulness. This share drops to 34 percent if help were needed to use the toilet; to about 26 percent if the person could not dress or bathe alone; to 24 percent if in the late stages or a terminal illness or if daily medical assessment were needed; and to about 19 percent if a person who had been providing assistance became unable or unwilling to do so.

For those who would move from a current home in the hypothetical circumstances, most indicated that they would choose a nursing home or assisted living residence. Ten percent or fewer said they would move in with a relative or friend under any of the given circumstances,

and this response was particularly unlikely in a situation of terminal illness (with less than four percent choosing it).

An assisted living residence was the most frequent choice only when the hypothetical problem was confusion or forgetfulness: 36 percent of respondents said they would choose an assisted living setting in that situation. Just slightly fewer respondents chose to remain in their homes under those circumstances; in contrast, just 15 percent indicated that they would opt for a nursing home if they became confused or forgetful enough to be in danger. More than three in ten said they would choose assisted living if they needed daily medical assessment, or if a caregiver became unable or unwilling to continue providing assistance. Very few people – just 8 percent – said they wanted to move to an assisted living residence in the late stages of a terminal illness.

The move to a nursing home was most likely to be chosen in a situation of terminal illness, with 43 percent indicating that this is where they would live given that situation. A nursing home was also more likely to be chosen than any of the other options if the person could not dress or bathe without help (40 percent); if daily medical assessment were needed (38 percent); or if a caregiver became unable or unwilling to continue providing assistance (39 percent). Nursing home care was least often chosen if help were needed with household tasks or meal preparation (about 9 percent), or when confusion or forgetfulness were creating dangerous situations (15 percent).



Individual characteristics affect responses

Not surprisingly, married survey respondents were significantly more likely than their unmarried counterparts to opt for getting help where they now live in every set of circumstances listed. For three of the seven scenarios²⁶, being married increased the option to stay at home by more than ten percentage points. Being younger also made a significant difference: People under 75 were more likely than older people to say they'd seek help in their homes, except if they needed daily medical assessment or if a caregiver became unable or unwilling to help. In general, those with more than a high school education were more likely to choose getting help at home, although most of these differences were not statistically significant. Race (being

²⁶ The three scenarios are "If you needed help to use the toilet" (15 percent difference between married and unmarried people's responses); "If you were in danger because of being confused, forgetful (14 percent); and "If you could no longer do household tasks or prepare meals" (11 percent). Note that all of the differences in married and unmarried people's responses to these questions are statistically significant.

white or nonwhite) and gender made no significant difference in the choice of getting help at home.

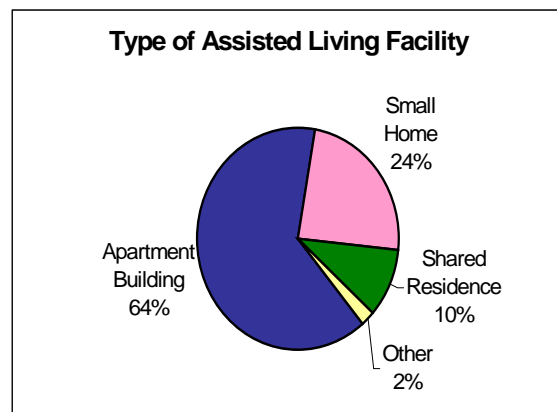
Some of the other residential choices were more strongly and consistently impacted by differences in individual characteristics. While few people overall indicated an intention to move in with a relative or friend under any circumstances, the oldest respondents, those who were unmarried, and those with a high school education or less were significantly more likely than their counterparts to mention moving in with a relative at least once. Women, younger people, more highly educated people, and whites were significantly more likely to mention moving to an assisted living residence at least once. In fact, people under 75 and whites were more than 20 percent more likely than their counterparts to opt for assisted living in at least one scenario.

Economic status makes a difference, as well. Having higher income, a higher home value, and owning a home all increase the chance that a person will choose to get help at home in every scenario²⁷. People who own their homes are about 15 percent more likely than renters to say they will stay in their homes if they cannot do household tasks or prepare meals, become confused or forgetful, or need help with going to the toilet. Each of these economic factors also decreases the chance that respondents will opt for a nursing home in any circumstance. Interestingly, having a larger pool of assets did not have a consistent or significant effect on the responses to these questions.

What do older people look for in Assisted Living?

Those who responded to at least one scenario by saying they would prefer to move to an assisted living residence were asked a series of follow-up questions about the specific characteristics they would seek in such a dwelling. In all, 855 respondents (about 59 percent) mentioned assisted living at least once in naming their residential options.

Nearly two-thirds (64 percent) of those who indicated interest in assisted living said they would prefer to have their own separate unit in an apartment building. About a quarter (24 percent) preferred a "small home" with only a few people, and about 10 percent chose a larger residence with shared living spaces. Asked what size facility they would prefer, 16 percent said one with fewer than five residents; about 30 percent said one with 5 to 8 residents; another 30 percent preferred nine to 20 residents; and 16 percent said 21 to 50 residents. Just eight percent would choose a facility with more than 50 residents.

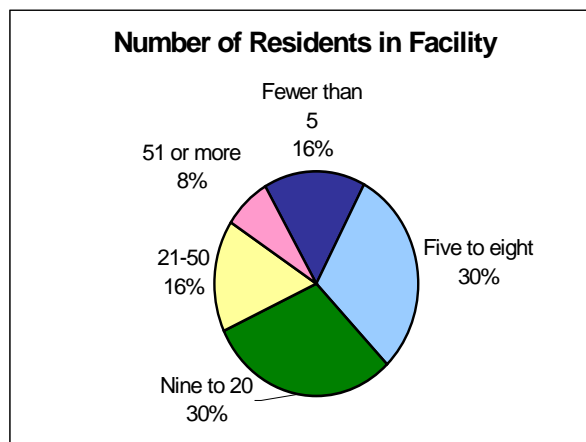


Given a situation in which they would not be rooming with a spouse, close friend or relative, three quarters of respondents (77 percent) indicated that they would chose a private room or to live alone in an assisted living residence. About five percent would prefer a shared room, and

²⁷ These differences are statistically significant in three of seven scenarios for the high income and high home value groups, and in four scenarios for home owners versus renters.

18 percent said it would not matter. Those who said they'd prefer to live alone were asked to rank the importance of a private room on a scale of one (very important) to five (not important at all). About two in three said "very important," and 85 percent gave this issue a rank of two or better. Just two percent rated it "not important at all."

Using the same scale, these respondents were asked to rank the importance of a private bathroom. Almost three-quarters ranked this "very important," and 87 percent gave it a rank of two or better. Everyone mentioning assisted living was asked how important it was to have cooking facilities in their unit. Just 22 percent said it was "very important," and about one third ranked this feature with a two or better. On the other hand, almost one in three (32 percent) rated it "not important at all."

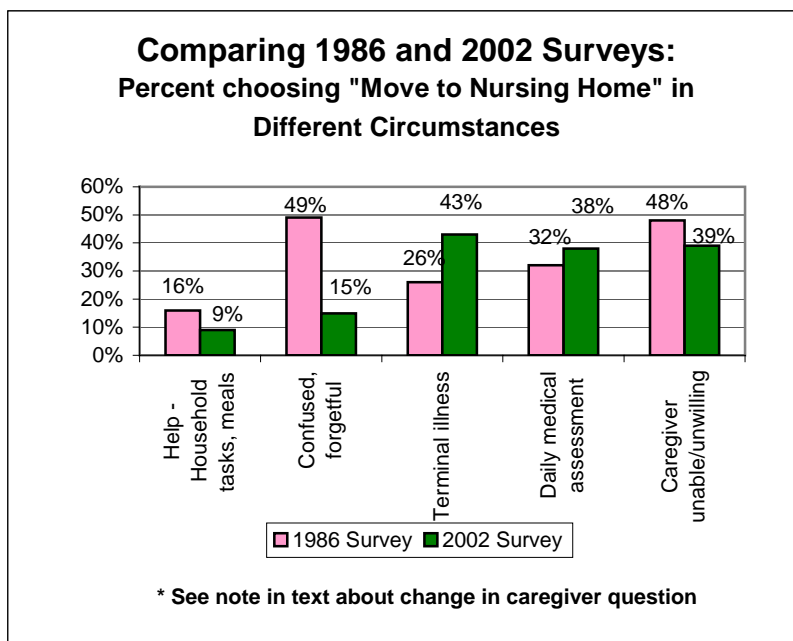


Comparing 2002 choices to 1986 survey results

These responses can be broadly compared to the results of a similar survey of Wisconsin adults taken in 1986. In a special supplement to the Wisconsin Health Status Survey²⁸ that year, all adults age 40 and older were asked to indicate their options given a set of health and self-care limitations. While the younger sample in 1986 and some important differences in the two surveys' questions make precise comparisons impossible, the general findings of the two surveys are similar.

People generally prefer remaining in the community (at home, with a relative or friend, or in an assisted living or hospice setting) rather than moving to a nursing home. In both years, the strength of this choice varied widely depending upon the specific circumstances prompting a decision.

Respondents to both surveys were least likely to choose a nursing home if their ability to do household tasks and prepare meals became limited. In both years, respondents were least likely to say they would move in with a relative or friend. And in both years, the choice of a nursing home was stronger when



²⁸ This survey continues to be taken on an ongoing basis, and is now known as the Family Health Survey, administered by the DHFS Division of Health Care Finance, Bureau of Health Information. The residential preference questions have not been repeated since 1986.

personal care needs were greatest – or if caregivers became unwilling or unable to provide sufficient care.²⁹

On the other hand, results of the two surveys differ in some noteworthy ways. The choice of a nursing home was cut in half over the 15 year interval for those needing help with household tasks and meals (from 16 percent to eight percent). And nursing home choice declined sharply – from 49 percent to just 15 percent - in situations where confusion or forgetfulness create problems or danger for respondents. In addition, while 1986 respondents were more likely to choose remaining at home over all other non-nursing home options, 2002 respondents chose moving to an assisted living residence over staying in their current homes in three of seven scenarios. These differences probably stem from the proliferation of assisted living options and a growing public familiarity with these facilities and services.

Another major difference in the two surveys involves the “late stage terminal illness” scenario. The share of people choosing nursing home care in this hypothetical circumstance has increased from 26 percent in the 1986 survey to 43 percent today. Indeed, more people chose “nursing home” in this situation than in any other 2002 scenario. The shift is surprising, given the growth and increasing familiarity of hospices (15 percent in 2002 indicated they would choose “hospice” if terminally ill³⁰). It may be due to broader changes in the role of nursing homes, many of which compensate for declining long-term resident populations by developing specialized acute care and end-of-life services and working with hospices to provide comprehensive care.

²⁹ The information about losing a caregiver is not precisely comparable in the two surveys. In 1986, respondents were asked two separate questions about their preferences if caregivers became (1) unable or (2) unwilling to continue providing care. When caregivers were unable, 38 percent chose nursing homes. When they were unwilling, 48 percent chose nursing homes. We’ve chosen the higher figure pertaining to “unwilling” caregivers for comparison because the 2002 question combined the two issues, asking about caregivers who were “unwilling or unable to continue providing care.”

³⁰ Hospice was not presented as a residential option, since it can be provided in any residential setting, but many respondents stated it as their choice without prompting. This indicates both the widespread familiarity of the concept, and a general misunderstanding of “hospice” as a place rather than a program or integrated approach to end-of-life caregiving.

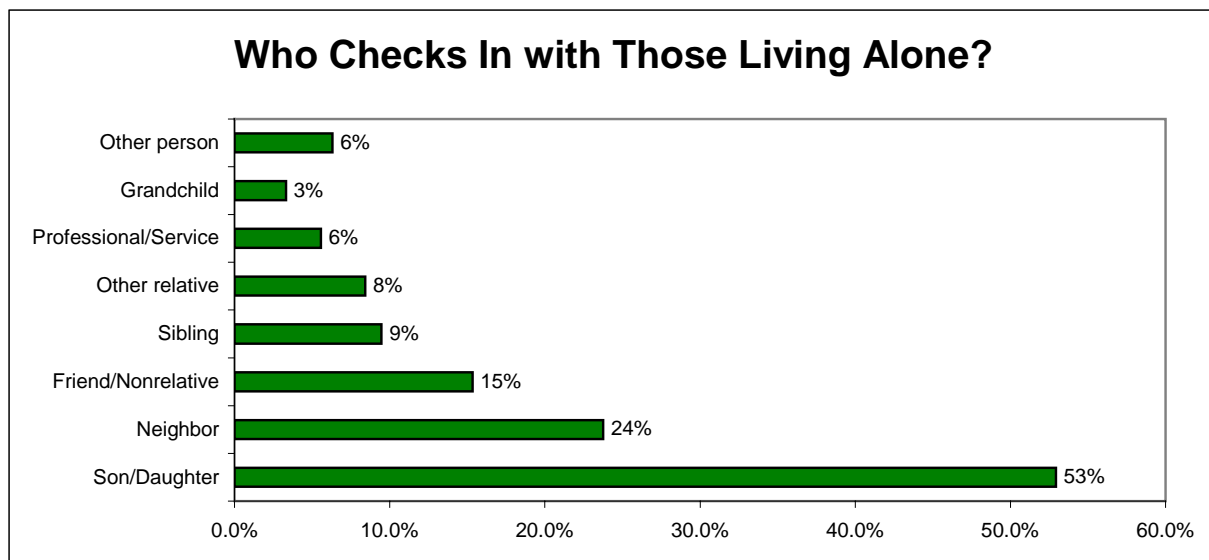
Getting Help: Connections to People and Programs

By the age of 85, and often several years earlier than that, many older people need some form of assistance to be able to continue living independently in the community. The kinds of help needed vary widely based on individuals' health, financial status, residential setting, and other factors. Some older people have families, friends, and other acquaintances to supply needed help with tasks ranging from home repairs to the annual yard cleanup to daily meals and personal care. Others get help from community sources, or purchase professional services. The survey asked about the sources older people turn to for help, and about their familiarity with information and assistance available to them through the aging network and the long-term support system.

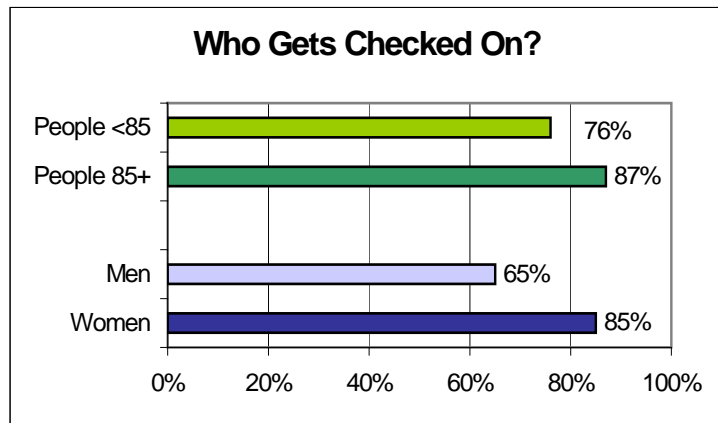
Checking in

Individuals living alone are the most likely to require some kind of assistance as they get older. They are also at greater risk of a minor incident, like a fall or sudden illness, becoming serious because help is not immediately available. Almost half of the respondents to our survey (46 percent) were living alone at the time of their interview. They were asked, "Is there anyone who regularly checks in with you, who would find out if you unexpectedly needed help?" While most (80 percent) said yes, one in five said they did not have anyone watching out for them in this way.

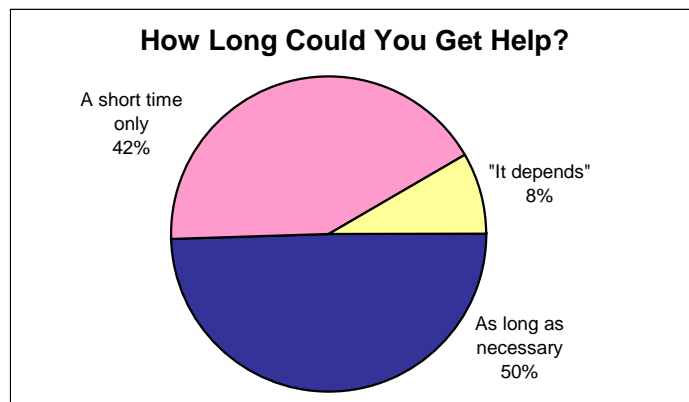
Respondents' children were the most frequent contacts in this regard: a little more than half (53 percent) of all people living alone said they had a son or daughter who checks in with them regularly. Almost one quarter (24 percent) had a neighbor who checked in on a regular basis, and about 15 percent had a friend or other non-relative. Smaller numbers reported regular contact with siblings (nine percent), grandchildren (three percent), other relatives (seven percent), or "someone else" (six percent).³¹ About two percent said that they had access to a "Lifeline," allowing them to make an immediate connection with professional help if necessary.



Gender and age made significant differences in people's responses to this question. Eighty-five percent of women versus 65 percent of men said someone regularly checked in with them, and the oldest respondents (age 85 and older) were more likely than younger ones to have someone checking in with them (87 percent compared to 76 percent).



The survey asked everyone (not just those living alone) whether they know someone, like a relative or friend, who would help them if they were ill or disabled and needed help for a week or more. About nine in ten respondents said yes, although 11 percent said they did not have an informal source for this kind of intermediate-term care. About half (49 percent) of those who did have access to assistance said they would be able to get this help for as long as



necessary, but 42 percent said they could count on help for a short time only, and eight percent said that "it would depend" on the situation or length of time required. There were no significant differences in the responses to this question based on gender, age, or other demographic characteristics.

Of the 89 percent who said they could get this kind of help, the largest share indicated that their son or daughter would be the source of help (69

percent). Note that, as with all sources of this type of help, children were mentioned more often by unmarried respondents (71 percent) than by currently married ones (67 percent). For those who were married, spouses came second, with 55 percent of married people mentioning their spouses.³² Siblings followed, mentioned by 16 percent of unmarried and seven percent of married people. Next came friends (17 percent and seven percent respectively), other relatives (14 percent and seven percent), and neighbors (10 percent and six percent).

³¹ Respondents could "check all that applied" in response to this question, so answers do not total 100 percent.

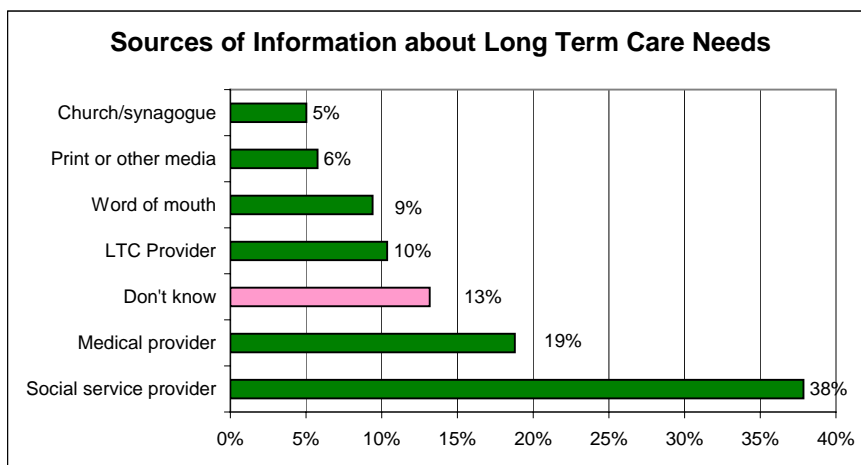
³² The survey did not prompt with response options, but rather allowed people to offer whatever came to mind. Therefore, the fact that many married people did not mention spouses is not a clear indication that they do not expect this help at home. Rather, respondents may have taken a spouse's help for granted, feeling it did not need to be stated. Future surveys should revise this question for married individuals, asking "Besides your spouse, is there someone who would help you if you were sick or disabled and needed help for a week or more?"

Current forms and sources of help

Fewer than one in ten respondents said that they were getting help at the present time with food, money, rides, or anything else. As with the other questions about getting help, sons and daughters were the most common source of assistance, mentioned by 57 percent of those getting help. The most common type of current help was with transportation, mentioned by 64 percent of those getting help (about five percent of all respondents). Next came help with food, mentioned by 27 percent of those getting help; very small numbers mentioned getting help with general household chores (18 percent of those getting help) and with money or financial matters (nine percent).

Getting more information and help

Those who remained relatively self-sufficient at the time of their interviews³³ were asked, "If you had to arrange for more care or help than your family or friends can provide, how would you find out about help available in your community?" Responses were recorded verbatim and later grouped into categories. The process of reading each response to assign it to a category revealed that a majority of people could not provide a ready answer to this question. Thirteen percent stated explicitly that they did not know or had "no idea" where to go for information. In fact, "Don't know" was the second most common response, following medical professionals, mentioned by 17 percent (e.g., "I'd ask my doctor"). A number of specific types of social service, aging, and "welfare" providers were each mentioned by five to 10 percent of respondents. When these are added together, a total of 38 percent said they would use one of these sources. Relatives, friends, and word-of-mouth came next (nine percent), followed by nursing homes (about five percent).



In general, responses suggest that people simply had not thought about this issue before being asked outright. The fact that the largest number of individuals said they would get information from doctors or other medical professionals also indicates that they interpreted this as a question about health – or that they imagine the type of help or care they may someday need as being health-related, rather than in the broader realm of long-term supportive services. Finally, it shows that many older people trust medical professionals and look to them as sources of assistance and guidance.

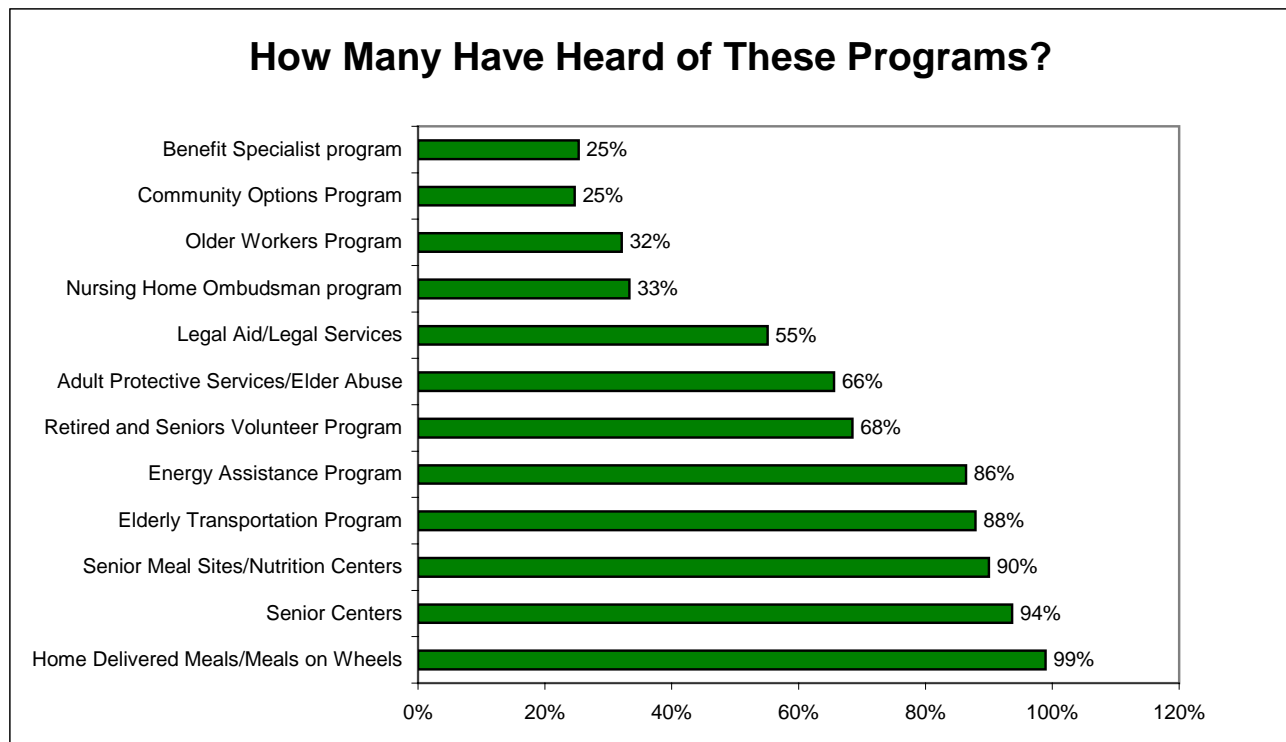
Program familiarity

Given the lack of quick reference to aging organizations as sources of help or information, it is somewhat surprising to find that when prompted with the names and brief descriptions of

³³ Another set of questions, detailed elsewhere, were asked of those who need assistance with basic activities of daily living, such as eating, bathing, or getting around the house.

specific Wisconsin aging programs, a substantial share of respondents said they had heard of them. Almost every respondent (99 percent) had heard of home delivered meals, sometimes known as “Meals on Wheels.” Most had also heard of senior centers (94 percent), senior meal sites or nutrition centers (90 percent), the Elderly Transportation Program (88 percent), Energy Assistance (86 percent), the Retired and Seniors Volunteer Program (68 percent), Adult Protective Services or Elder Abuse Services (66 percent), and Legal Aid/Legal Services (55 percent).

While fewer than half had heard of the other programs mentioned, all were familiar to a substantial portion of the survey group (even the least-recognized programs, Elderly Benefit Specialists and the Community Options Program, were familiar to one quarter of respondents). Thus, despite people’s inability to quickly come up with sources of help or information about help, these results indicate general awareness of program options available to older people through county agencies across the state.³⁴



On the other hand, only one quarter of respondents (26 percent) said they had ever used any of these programs. Older people, unmarried people, women, and people with lower income³⁵

³⁴ Note that the large number of “Yes” responses to these questions could be an artifact of the interview process. Interview subjects are known to provide “favorable” answers to certain kinds of questions, notably those they believe reflect on the interviewing organization. This set of questions is subject to biased responses because many of the programs mentioned are administered by the survey sponsor (Department of Health and Family Services Bureau of Aging and Long Term Care Resources).

³⁵ Programs funded through Title III of the Older Americans Act (Administration on Aging) are available to all persons age 60 and older, regardless of income or assets, so everyone surveyed was qualified to participate in them. These include home-delivered meals and meal sites, Adult Protective Services/Elder Abuse program, and the Benefit Specialist program. Other programs target lower-income individuals and

and fewer assets were significantly more likely to have used at least one aging program. Most (81 percent) of those who had not yet made use of any program said that they would consider doing so. In contrast to the way demographic factors affected the likelihood of actually participating in programs, married people and younger people were the most likely nonusers to say they would consider using them. Gender did not make a difference in this response; nor did income or assets. The largest share of those who said they would **not** consider using these aging programs explained that they did not need assistance (54 percent), or were too busy and active already to take part in more activities (10 percent).

Transportation services

Because many aging organizations are working to develop or enhance their transportation programs, a number of additional questions inquired about older people's need for and use of these services in particular. First, people were asked how they usually get places outside of walking distance. A large majority (85 percent) of respondents either drive or are driven by a spouse. Another 11 percent get rides or borrow cars from friends. The remainder mostly take busses (two percent), with a few people using taxis or special "senior or disabled vans," or walking or bicycling to their destinations. In all, fewer than two percent of those surveyed said they had trouble getting transportation when they needed it. Most of the problems involved the availability or convenience of transportation options. Not one person mentioned the cost of transportation or rides as a problem.

In all, 21 people said they needed special transportation equipment or services. Their specific needs were divided about evenly between wheelchair lifts, wheelchair storage, and door-to-door service.

most of the survey respondents would not qualify (these include the Community Options Program, Older Worker Program, Energy Assistance, Retired and Seniors Volunteer Program, and Legal Aid/Legal Services, among others).

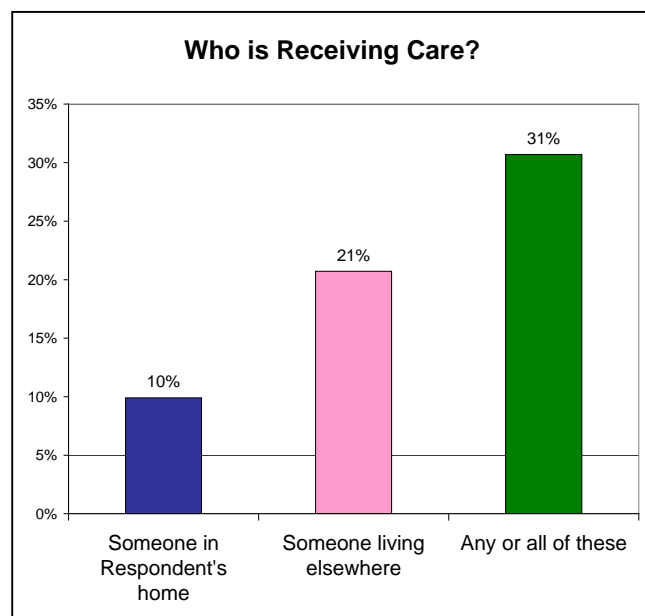
Older Caregivers: Helping Others

Many people envision their retirement years as the time to reap the rewards of a life spent supporting and caring for others. But for a growing share of older people, caregiving continues to play an important role. Stories abound detailing the “squeeze” felt by Baby Boomers with simultaneously needy offspring and parents, and demographers are warning about the probability that this group will experience significant caregiver stress into their later years. But what about those just ahead of the Baby Boom – today’s 65-plus population?

Respondents were asked about their experiences in this area. Altogether, about 31 percent of all respondents reported having at least one kind of caregiver responsibility: caring for a disabled child, for someone living with them in their home (such as a spouse), or for someone living elsewhere (a relative, friend, or neighbor, for example). Men and women were equally likely to report being caregivers for at least one person. Younger respondents and those with more education were significantly more likely to report at least one kind of caregiving. Married people were twice as likely as unmarried ones to have these responsibilities, because one of the largest categories of caregiving involves married people caring for ill or disabled spouses.

Helping Co-Residents

About one in ten respondents said they were the main caregiver for someone disabled or in ill health who lives with them in their home, and in almost all of these cases (89 percent) the care recipient was a spouse.³⁶ The median age of those caring for disabled or ill spouses was 72 years, and the median age of their spouses was 74 years.³⁷ Men cared for spouses more often than women: about 11 percent of men and eight percent of women said they were the primary caregiver for a disabled or ill spouse.³⁸ Very small numbers of respondents provided care in their own homes for disabled or ill parents, sons or daughters, grandchildren, siblings, or others. Overall, the survey found few “extended families” living under one roof: Of all 1,453 respondents, just ten had parents living with them; eleven lived with siblings; 43 had live-in grandchildren (about three percent), and 134 had sons or daughters living with them (about nine percent).



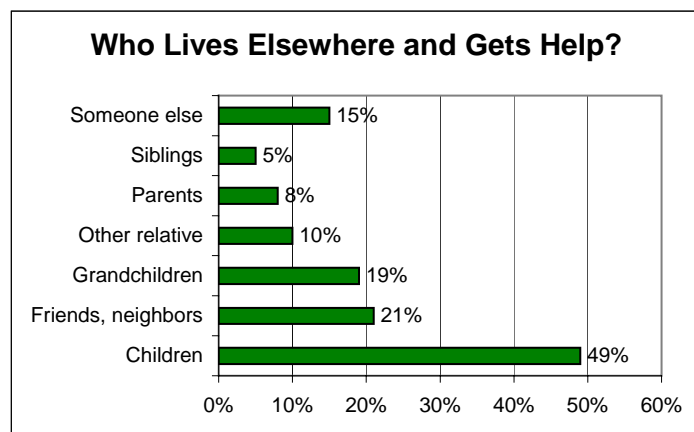
³⁶ This proportion may be higher. It was not possible to determine the identity of the care recipient in about five percent of the cases (7 in all).

³⁷ Median age of the full sample of respondents is 73 years.

³⁸ This difference is significant at the $p < .05$ level.

Helping people living elsewhere

The survey also asked, “Do you provide any kind of unpaid help or care on a regular basis for anyone who lives somewhere else? For example, do you help with babysitting, money or



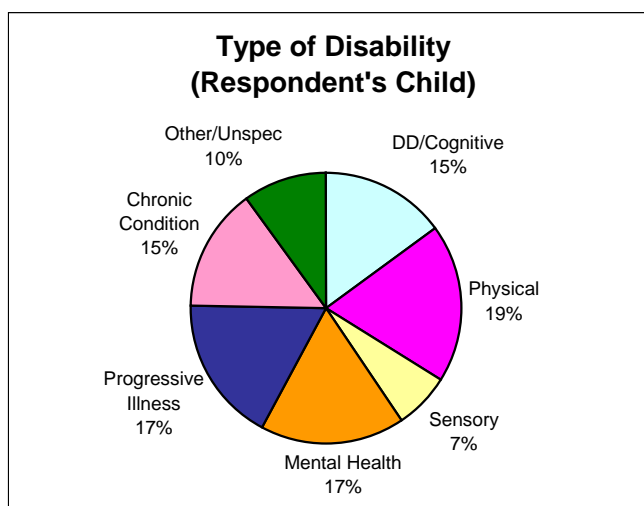
paying bills, chores, or any kind of nursing care?” A total of 21% of respondents reported that they help or care for someone who does not live in the same house with them. The most common recipients of this help were their own children (49 percent of those providing this kind of help, or 10 percent of all respondents) and grandchildren (19 percent of those providing help, or four percent of all respondents). Taken all together, parents, siblings, and other relatives were helped by about five percent of all respondents. Seven

percent help nonrelatives or unspecified other people, and about two percent reported that they “help” people who live elsewhere in general by participating in organized volunteer work.³⁹

Respondents whose sons or daughters have disabilities

A special set of questions addressed the ongoing caregiving responsibilities of older people whose sons or daughters have disabilities. Thanks to advances in health care and in social, technological, and economic supports, people with many kinds of disabilities now have the opportunity to live permanently in the community. It has become rare to commit children with disabilities to institutions, and many institutions are closing or downsizing, discharging long-term residents. Life expectancies have greatly improved for persons with disabilities as well. As a result, family members, and parents in particular, may play a lifelong role in supporting loved ones with disabilities.

Of all survey respondents with living children (88 percent had at least one), almost one in ten had one or more with a disability. Most of these had one disabled son or daughter, but about 11 percent had two or more children with disabilities. A large majority of these offspring (93 percent) were adults between the ages of 25 and 64, and more than half (53 percent) were age 45 or older. The conditions these parents labeled as disabilities were about evenly divided between physical disabilities (19 percent); progressive illnesses (including cancer, MS, and muscular dystrophy – 17 percent



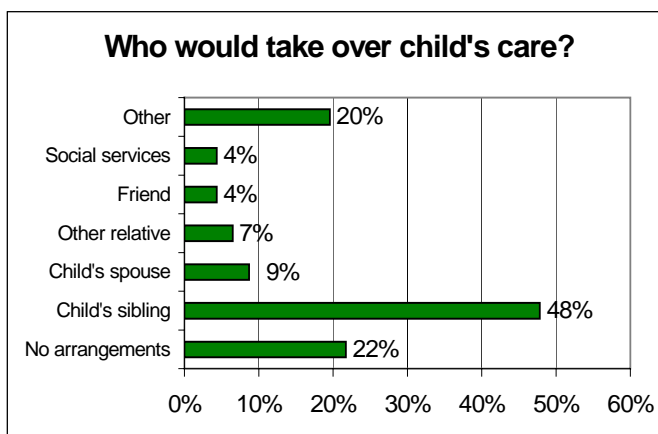
³⁹ Respondents could provide multiple answers to the question of who they helped or cared for, so these responses will not total 100 percent.

in all); mental health problems (17 percent); developmental or cognitive disabilities, including brain injuries (15 percent); and chronic illnesses like diabetes and heart disease (15 percent). A smaller number (seven percent) had sensory disabilities such as blindness or deafness, and the remainder had unspecified conditions.

Parents were not asked to gauge the severity of their sons' or daughters' disabilities, but information about living arrangements provides a sense of overall capabilities. Six in ten were living independently, but 23 percent lived with their parents. Most of the rest lived in group or foster homes (about six percent) or institutions, including nursing homes (about five percent), with a few in unspecified living arrangements.

About 38 percent of parents whose sons or daughters had disabilities either provided care or supervised the care of their child. About 16 percent helped out daily. When the entire survey sample is taken into account, this means that three percent of all respondents were providing care or supervision for a son or daughter with a disability, and about one percent of all respondents had daily caregiving responsibilities.

Parents were asked whether arrangements were in place for someone else to supply their son's or daughter's care, should they become unable to do so. Most of those currently providing some care said yes, although 22 percent said that no such arrangements had been made. The most common alternate caregiver was the child's sibling: 48 percent of parents with caregiving responsibilities indicated that a sibling would take over care if necessary.



Almost half (46 percent) of the respondents who provided or supervised care for a son or daughter with a disability were helping or caring for at least one additional person, as well. These individuals were considerably more likely to do so than were respondents who did not have caregiver responsibilities for disabled offspring. Of the latter group, 28 percent were caring for or regularly helping someone else.

Summary and Discussion

These survey results indicate a number of topics requiring closer attention from those working with older people, providing supportive services targeted for this population, and developing aging-related policy and program initiatives.

In the area of ***health and health care utilization***, this survey's data on falls and fall-related injuries fills an important gap in our knowledge about this particular health risk to older people. Previously, our knowledge about falls was limited to information about those hospitalized, institutionalized, or killed due to fall-related injuries. This survey suggests that it is quite common for older people to fall – with one in five experiencing a fall to the floor or ground in a year's time. The majority of these cases do not end up in hospital or mortality datasets in a given year, but it is well-known that those with a history of falling are likely to fall again. These findings affirm the importance of fall prevention programs for the older population.

With regard to ***economic well-being and preparedness***, these survey results underscore older Wisconsin residents' reliance on Social Security income first, and pensions second, as major income sources. With one in four older people reporting very limited financial assets (less than \$12,000), and more than half reporting less than \$50,000 in assets, income security clearly depends upon organized programs and not individual savings. For older women, more limited access to pensions, smaller accumulated assets, and a greater likelihood of being widowed all create obstacles to economic security and independence. Financial education and planning targeted to older people, and women in particular, could help stave off economic crises in this population.

A surprisingly large share of Wisconsin's older population reports having completed advance planning documents, such as advance directives for health care and durable power of attorney for finances. Still, about four in ten have not done so, and about the same number have not discussed their wishes for their health or financial futures with family or friends. Improving these numbers will benefit individuals, families, and the community as a whole. These findings suggest a useful role for information services and assistance in working through life-planning processes, and in completing the legal documentation to ensure that older people's wishes are clearly understood.

This survey's exploration of ***current housing and residential options*** suggests, among other things, that older people need better information about the alternatives and choices available to them as they age. Most other studies of this issue have found very strong general attachment to the idea of "staying in my home forever." But this survey's approach, by emphasizing specific challenges to continued self-care in the home, prompted very different responses. Most people "opted out" of staying in their homes in the face of hypothetical challenges for which concrete solutions are widely available. Three efforts could alter these responses dramatically:

- Outreach to provide information about these solutions
- Improvements in the delivery and quality of home-based long-term support services
- Measures to diminish any social stigma surrounding them

There is precedent for this kind of effort: increased availability and awareness of assisted living residences and of hospice services between 1986 and 2002 made a significant difference in the results of similar survey questions asked in the two years.

Information and assistance efforts could also change the way people respond to questions about ***getting help – connections to people and programs***. Many of the public programs asked about in the survey are designed to enhance older people's ability to "age in place," staying in their longtime homes or in independent residences of their choosing. People are obviously more likely to tap into services they know about. They are also more likely to inquire about help if they know whom to call for information, and this section of the survey particularly highlights the need to get "first call for supportive services" information into the hands of older people. With about one in eight older people expressing complete lack of knowledge about sources of help, basic outreach is clearly needed. Since another 17 percent say they would turn to their doctors for help, it is important to get information about long-term supportive resources into the hands of medical professionals as well.

A number of recent studies have underscored the risks and costs of caregiving, particularly for older people without significant outside help or support. On the other hand, when well-supported, caregivers can reap important social and emotional benefits from their ongoing, meaningful involvement in other people's lives. This survey's questions about ***older caregivers – helping others*** show that nearly one third of older people report some caregiving responsibilities, mostly involving family members. These numbers are almost certain to expand over time, as the number of very old people and of aging disabled adults increases. Ongoing development and expansion of supportive services can help reduce the stress-related costs of this care and its health and emotional consequences.

Caring for adult offspring with disabilities may present particularly stressful concerns for aging parents. Many older people who provide or supervise care for sons or daughters with disabilities reported that their child's sibling would take over if they themselves became unable to continue this care. The survey did not ask whether the siblings were aware of this hope or expectation, but it is not difficult to imagine that these expectations are unstated in some families and disputed in others, leading to increased stress for caregiving parents facing the future. Supportive services can also play a role in raising these questions and facilitating discussion within families that have these concerns.

Profiles of Older Wisconsin Residents

Survey Questions

PRELIMINARY SCREENING QUESTIONS:

1. Is anyone living here age 65 or over?
2. How long have you lived in Wisconsin?
3. Do you live in a different state for any part of the year?
 - 3A. (if yes) Which other state do you live in?
 - 3B. How many months will you spend in Wisconsin this year? _____

GENERAL DEMOGRAPHICS/HOUSEHOLD GRID

First name	Relation to R	Age	Sex	Marital Status	Education	Race/ Ethnicity	Employed?
	Categories		M/F	Categs.	Categories	Categories	FT/PT/no
							FT/PT/no
							FT/PT/no
							FT/PT/no
							FT/PT/no

HELPING OTHERS

4. Most of the questions in this survey will be about you, but we're going to start with a few questions about ways you might be involved in helping or caring for others. We are trying to get a sense of how many older people have responsibility for helping others. First, do you have any living children?
5. (if yes) Do any of your children have a long-term disability, such as a physical or developmental disability, or a serious mental health or emotional problem?
 - 5A. (if yes) How many of your children have a disability?
 - 5A_1. (if one) How old is he/she?
 - 5A_2. (if more than one) How old is the one who needs the most help from you or others?
 - 5B. Do you (and your spouse, if R is married) provide any kind of help or care for your son/daughter, or supervise his/her care?
 - 5C. Does this child need your help or supervision daily, or less often?
 - 5D. Where is he/she currently living? (open-ended, prompt if necessary)
 - 5E. (if yes to 5B) If you (and your spouse, if R is married) became unable to care for your son/daughter or to supervise his/her care, is there someone who would take over this responsibility?
 - 5E_1. (if yes) Who? (open-ended, do not prompt)
 - 5F. What type of problem or disability does he/she have? (open-ended)
 - 5G. (ask if more than one child with disability): What type of problem or disability does your other child have?
6. (Ask only if NOT living alone AND if no disabled child living at home) Are you the main caregiver for anyone disabled or in ill health in your home?
7. (Ask only if there IS a disabled child living at home AND at least one other person (total 3 or more) living at home) Are you the main caregiver for anyone ELSE disabled or in ill health in your home?
 - 7B. (if yes to either 6 or 7 and lives with more than one person) Which person is that?

8. Do you provide any kind of unpaid help or care on a regular basis for anyone who lives somewhere else? For example, do you help with babysitting, money or paying bills, chores, or any kind of nursing care?

8A. (if yes) Who do you help out in this way? You can include everyone you help. (open-ended, do not prompt)

GENERAL HEALTH

9. In general, do you feel your own health is excellent, good, just okay, not so good, or poor?

10. Have you been unable to carry out your usual activities at any time during the past month because of illness or some other health-related problem?

10A. (if yes) What was the problem? (open-ended - do not prompt)

11. Have you been told by a doctor that you have a serious health problem, such as asthma, diabetes, stroke, heart disease, cancer, or another serious problem?

(if yes) What problems has a doctor said you have? (open-ended - do not prompt)

12. Do you have any problems with blurred or failing vision that are not solved by wearing glasses or contact lenses?

12A. (if yes) Are you legally blind?

13. Do you have a hearing problem, or hearing loss?

14. Do you have any problems with dizziness or losing your balance?

15. Do you have any problems with numbness, tingling, or weakness in your legs or feet?

16. Do you have any serious memory problems?

17. Do you take any medications that make you drowsy or affect your thinking or driving in any way?

18. What kind of exercise do you do on a regular basis? (open-ended, do not prompt, mark all that apply)

ACTIVITIES OF DAILY LIVING:

20. Do you have any trouble dressing, bathing, eating, or using the toilet because of a health problem or disability?

20A. (if NO to 18): Do you have trouble with regular household activities such as doing laundry or housework, preparing meals, or shopping for groceries?

NOTE: The rest of this section is **skipped** for those answering NO to both question 20 and question 20A.

21. In general, does anyone help you get in or out of bed?

21A. (if yes) Who helps?

21B. (Everybody) Do you use a cane, walker, wheelchair, mechanical lift, or any other device to help you get out of bed?

22. In general, does anyone help you get around inside the house?

22A. (if yes) Who helps?

22B. (Everybody) Do you use a cane, walker, crutches, wheelchair, scooter, or chairlift on the stairs for getting around inside the house?

23. In general, does anyone help you get and put on the clothes you wear during the day?

23A. (if yes) Who helps?

24. In general, does anyone help you bathe or wash?

24A. (if yes) Who helps?

24B. (Everybody) Do you use a shower chair, tub bench, grab bars, or other equipment to help you bathe?

25. Do you usually prepare your own meals?

25A. (If no) If you had to do prepare your own meals, could you?

- 25B. (If no) Is the reason you don't do prepare your meals because of a disability or health problem, or some other reason?
- 25C. (If no to 25) Does someone usually help you prepare meals, or do it for you?
- 25D. (If yes) Who is that?
26. Do you usually shop for your own groceries; that is, go to the store, select the items, and get them home, or order deliveries?
- 26A. (If no) If you had to shop for groceries, could you?
- 26B. (If no) Is the reason you don't shop for groceries because of a disability or health problem, or some other reason?
- 26C. (If no to 26) Does someone usually help you shop for groceries, or do it for you?
- 26D. (If yes) Who is that? (prompt for relationship to R)
27. In general, does anyone help you eat?
- 27A. (if yes) Who helps?
28. In general, does anyone help you get to the bathroom or use the toilet?
- 28A. (if yes) Who helps?
- 28B. (Everybody) Do you use a raised toilet, portable toilet, or grab bars to help you with this?
- 28C. (Everybody) Do you use a pad, special underwear, or other protection because of trouble controlling urination?
29. Do you usually do your own laundry?
- 29A. (If no) If you had to do your own laundry, could you?
- 29B. (If no) Is the reason you don't do your laundry because of a disability or health problem, or some other reason?
- 29C. (If no to 29) Does someone usually help you with laundry or do it for you?
- 29D. (If yes) Who is that?
30. Do you usually do other heavy work around the house, such as moving furniture, scrubbing floors, or washing windows?
- 30A. (If no) If you had to do heavy work around the house, could you?
- 30B. (If no) Is the reason you don't do heavy work because of a disability or health problem, or some other reason?
- 30C. (If no to 30) Does someone usually help you with heavy work or do it for you?
- 30D. (If yes) Who is that?
31. Do you get around outside at all, either with help or without help?
- 31A. (If 31=no) If you had to get around outside, could you?
- 31B. (If 31=no) Is the reason you don't get around outside because of a disability or health problem, or some other reason?
- 31C. (If 31=yes) Does someone usually help you get around outside?
- 31D. (If 31C=yes) Who is that?
32. Do you usually manage your money by yourself, including things like keeping track of bills and handling cash?
- 32A. (If no) If you had to manage your money, could you?
- 32B. (If no) Is the reason you don't manage your money because of a disability or health problem, or some other reason?
- 32C. (If no to 32) Does someone usually help you manage money, or do it for you?
- 32D. (If yes) Who is that?
33. Do you need any help taking medication; that is, remembering to take the right medications at the right time, in the right amounts?
- 33A. Who helps you?

HEALTH CARE AND INSURANCE

36. Is there anything that makes it difficult for you to get the medical, mental health or dental care you need?

- 36A. (if yes) What makes it difficult? (open-ended, do not prompt; check all that apply)
37. Have you seen any kind of health care provider In the past 12 months?
38. Do you have any health or hospital insurance besides Medicare? This includes Medicaid, Medigap or any other insurance paid for by either you, an employer, or a union.
39. (IF yes to 38 - HAS insurance) Does your health insurance cover all, part, or none of the cost of the prescription drugs you need?
40. (Ask EVERYBODY: with and without health insurance) Approximately how much did you spend out-of-pocket in the past year on prescription drugs and medications, including any insurance deductibles or co-payments?
- 40A. Was this an average year, or was it low or high?
- 40B. (if low or high) How much would you say you spend in an average year?
41. Do you have a separate long-term care or nursing home insurance policy?

FALLS

It is common for people to fall occasionally as they get older, and falls can lead to serious health problems. We are trying to understand more about how and why people fall.

42. Have you fallen to the floor or ground in the last 12 months?
- 42A. (if yes) Did you fall once, twice, or more times in the last 12 months?
43. [if one fall] Where were you when you fell? (open-ended; prompt only if necessary)
- 43A. [if one fall] Why do you believe you fell? (open-ended, do not prompt)
44. [If more than one fall] Where were you when you fell the most recent time? (open-ended; prompt only if necessary)
- 44A. [If more than one fall] Why do you believe you fell the most recent time? (open-ended, do not prompt)
45. [If any falls] When you fell/in any of these falls, were you hurt so that it was hard for you to do regular activities for 7 days or more?
- 45A. (if yes) What kind of injury did you have? (open-ended)
- 45B. Did you seek medical care for this injury?
- 45C. (If responded 45A_4 through 45A_8 for injury type) Would you say the injury resulted in a disability?

GETTING HELP

46. (Ask only of those who live alone) Is there anyone who regularly checks in with you who would find out if you unexpectedly needed help?
- 46A. (if yes) Who would that be? (open-ended; check all that apply)
47. Is there someone – like a relative or friend – who would help you if you were sick or disabled and needed help for a week or more?
- 47A. (if yes) Who would that be? (open-ended)
- 47B. If you needed it, would you probably get help from them for as long as necessary, or only for a relatively short time?
48. Is anyone helping you out now with food, money, rides, or other kinds of help?
- 48A. (if yes) Who? (check all that apply)
- 48B. (if yes) What kind of help? (check all that apply)
49. If you needed to arrange for more care or help than your family or friends can provide, how would you find out about help available in your community? (open-ended - check all that apply)

RESIDENTIAL OPTIONS

[NOTE: We made some minor changes to this text during pretesting. This approximates the questions asked using the final computerized version of the survey.]

Certain conditions can make people think seriously about what they want to happen if they can't manage on their own. I'm going to describe a series of situations and ask you to think about your choices in each one. If you already get help with any of these situations where you live now, you can just say that.

50. If you found you could no longer do household tasks or prepare a meal, would you choose to get help where you now live, move to the home of a relative or friend, move to an assisted living residence, or move to a nursing home?
 51. If you were getting into dangerous situations because of being confused or forgetful, would you choose to get help where you now live, move to the home of a relative or friend, move to an assisted living residence, or move to a nursing home?
 52. (SKIP this question if R answered YES to Q23 AND YES to Q24) Which of these would you choose if you were disabled to the point where you could not dress or bathe yourself?
 53. (SKIP this question if R answered YES to Q28) Which would you choose if you needed help to use the toilet?
 54. Which kind of residence would you choose if you had an unstable medical condition requiring daily assessment by a nurse or doctor?
 55. Which would you choose if you needed nursing care for the late stages of a terminal illness, such as cancer?
 56. If a friend or relative who had been providing your care at home was no longer able to, or no longer wanted to, which of these would you choose?
- Q57A: (Ask if responded "assisted living residence" for any of q50-56.) You mentioned an assisted living as one of your choices. There are several different kinds of assisted living residence. Would you choose to be cared for in a small home with only a few people, a larger residence with shared living spaces, or an apartment building with separate units?
- Q57B: (Ask if responded "assisted living residence" for any of q50-56.) Would you prefer to live in a place with fewer than five people, five to eight people, nine to 20, 21 to 50, or more than 50 people?
- Q57C: (Ask if responded "assisted living residence" for any of q50-56.) Assuming that you would not be rooming with a spouse, close friend or relative, which of the following would you prefer if you lived in a residential care or assisted living setting? A private room for you alone, a shared room with someone else, or it doesn't matter.
- Q57C_1 (If q57C = "a private room") If the number 1 means "very important" and the number 5 means "not important at all," what number would you give the importance of having a private room or unit for you alone?
- Q57C_2 (If q57C = "a private room") If the number 1 means "very important" and the number 5 means "not important at all," what number would you give the importance of having a private bathroom for you alone?
- Q57D: (Ask if responded "assisted living residence" for any of q50-56.) Assuming the assisted living facility you lived in had a dining room and meal service, how would you rate the importance of cooking facilities in your own room or unit? Again, the number 1 means "very important" and the number 5 means "not important at all."

PUBLIC SERVICES/PROGRAM PARTICIPATION/AWARENESS/LEGAL NEEDS

58. We are trying to get a sense of how widely Wisconsin's programs for older people are known. I'm going to describe several services and programs for older people. Please tell me whether you have heard of each program. First, have you heard of the Benefit Specialist Program, which provides legal advice and help with getting services and benefits like insurance, pensions, and Social Security?
59. Have you heard of Home Delivered Meals, or Meals on Wheels?
60. Have you heard of Senior Meal Sites, or the Elderly Nutrition Program, which serves low-cost meals at Senior Centers and other public places?
61. Have you heard of the Community Options Program, or "COP," which provides money for complete home care for frail older people?
62. Have you heard of the Nursing Home Ombudsman program, which handles complaints about care in nursing homes? [Interviewer note: Ombudsman is pronounced "ahm-buds'-men"]
63. Have you heard of the Retired and Senior Volunteer Program, or Foster Grandparents, or the Senior Companion Program, which provide opportunities for older persons to volunteer in schools and community services?

- 64. Have you heard of Legal Aid or Legal Services, which provide discounted or free legal representation?
- 65. Have you heard of the Energy Assistance Program, which helps pay for heat?
- 66. Have you heard of Adult Protective Services or Elder Abuse programs, which protect older people from abuse, neglect, and exploitation?
- 67. Have you heard of Senior Centers, which sponsor a variety of activities and services for older people?
- 68. (IF YES to any of 58 through 67) Have you yourself or has anyone in your household ever used any of these programs?
 - 68A. (if no) Would you consider using any of them?
 - 68B. (if no to 68A) Why not? (Open-ended, do not prompt)

MOBILITY AND TRANSPORTATION

- 69. How do you usually get to places outside of walking distance? (open-ended)
- 70. Do you need special transportation equipment or services?
 - 70A. (if yes) What do you need?
- 71. Have you heard of the Elderly Transportation Program, which provides vans and volunteer drivers to take older people to appointments or activities?
- 72. Do you have any problem getting transportation when you need it?
 - 72A. (if yes) What kind of transportation problem do you have? (open-ended; do not prompt)

HOME AND HOUSING

- 73. To help us interpret some of the earlier questions, I have a few questions on housing and where you live. What county do you live in?
 - 73A. Do you live in a town or city, or in the country?
- 74. How long have you lived at your current residence?
- 75. Do you live in a single-family house, a building with more than one unit, or a mobile home?
 - 75A. (if multi-unit building/apartment/condo): Is the building you live in especially for older people or people with disabilities?
 - 75B. (if yes) Are services available for meals, transportation, or social activities?
 - 75C. (if yes to 75A) Are services available for nursing or help with personal care, like with bathing?
- 76. Do you or your family own your home either with or without a mortgage, or are you renting it?
- 77. (renters) Do you live in a building that is part of a low-income or government housing program?
- 78. (everybody) Is your home in good repair, or does it need major repairs costing more than \$1,000?
 - 78A. (homeowners) Could you afford to make these repairs if you wanted to?
- 79. Do you feel safe living here?
 - 79A. (if no) Why not? (open-ended)

PLANNING

Earlier in our conversation we talked about the kinds of home care or housing you'd like to have if you couldn't take care of yourself alone. Now I'd like to ask about how you've communicated your wishes to people who are important to you. There are a number of documents that show your intentions in case you become unable to express yourself or make decisions.

- 80. Have you completed and signed a legal document called a Power of Attorney for Health Care, assigning someone to make health care decisions for you if you aren't able to?
 - 80A. (if no) Do you have a Living Will?
- 81. Have you prepared legal documents assigning someone to manage your property or finances if you aren't able to, such as a Durable Power of Attorney?
- 82. Aside from legal documents, have you discussed with friends or family members your wishes for your own future, particularly in the event you can't take care of yourself at home without help?

83. Do you believe your friends and family members understand and respect your wishes regarding your own future health decisions and care you might need?

EMPLOYMENT, INCOME AND ASSETS/RETIREMENT PLANS

84. At the beginning of the interview, you mentioned that you are [employed part-time, employed full-time, retired, a homemaker, unemployed, etc] I have some more questions about your current and previous jobs. Are you looking for work, or are you retired, disabled, or a homemaker?
86. (if retired) Sometimes older people retire from their main jobs, and then start working again part-time or at a different job. Have you taken any other job since retiring?
87. (If homemaker or disabled) Were you previously employed at paid work?
88. (If working, looking for work, or retired) What is (was, if retired) your main or usual job? That is, what was the general type of job? (I'm thinking of things like stock clerk, secretary, electrical engineer, administrator, etc.)
- 88A. What were your most important activities or duties on this job? (I'm thinking of things like clerical duties, running machinery, managing people, keeping accounts, etc.) (Open-ended, record text verbatim)
- 88B. What kind of business or industry was this? (I'm thinking of things like manufacturing, retail sales, health services, construction, etc.) (open-ended; record text verbatim)
89. (If working, looking for work) At what age do you think you will retire?
90. Have you heard of the Older Worker Program, also called Senior Aids or Title 5, that helps older people get jobs?
91. (If retired) Other than Social Security, do you now receive a pension from any former job you've had?
92. (If working AND said NO to q91) When you retire, will you receive a pension from any current or former job you've had?
93. (For all married respondents with EMPLOYED spouses) Other than Social Security, will your spouse receive a pension at retirement from any current or former job?
- 93x. (For all married respondents with retired or unemployed spouses) Other than Social Security, does your spouse now receive a pension from any former job?
- 93A. (if yes to EITHER 93 or 93x) If your spouse were to die, would his/her pension benefits continue to be paid to you fully, partly, or not at all?
94. (For all widowed respondents) Did your spouse receive a pension, or was he/she eligible to receive a pension, from his/her former employer?
- 94A. (if yes) When your spouse died, did the pension benefits continue to be paid to you fully, partially, or not at all?
- 94B. (For all who are NOT widowed OR never married) Do you receive any pension benefits from the employer of any former spouse who has died?
- 94C. (if yes) Are you receiving the full pension benefit, or a partial benefit from that source?
95. Did you (or your spouse, if married/widowed) lose any pension benefits due to a reorganization or merger involving your employer?
- 95A. (if yes) Was the amount of your pension reduced, or did you lose all pension benefits?
96. All in all, how well does your household's current income take care of your household needs – very well, fairly well, not very well, or poorly?
97. Do you generally have enough money or food stamps to eat balanced meals?
98. If the Medicaid program, also known as Medical Assistance or Title 19, would pay for your long-term care and then later collect those payments from your estate after you died, would you accept this assistance from Medicaid?
99. What is the MAIN source of income for you (and your spouse)?
- 99A. Is there another major source of income?
- 99B. What is that? (open-ended, prompt with categories if necessary)

100. (Unless R lives alone) You named (____ - number of, to be filled in automatically) people who live in this house. Do all of these people share the same income you live on?

100A. (if no) How many of the people living there share the income that you live on?
(number)

101. Finally, we have a few questions to help us get a general picture of the financial situation and problems of older people in Wisconsin. We ask questions about income and assets because we need to understand how many people may need help paying for long term care in the future. Information about any individual will never be shared with anyone.

Thinking about your total 2000 household income from all sources, was it greater than (*amount equal to 150% of 2000 poverty threshold for household of this size (rounded to nearest \$500); computer presents it based on number of persons in household), or (*) or less?

101A. (if greater) Would you say that your 2000 household income was less than (*200% of poverty), between (*200% and 300%), between (300% and 400%), or more than (*400%)?

101B. (if less) Would you say that your 2000 household income was less than (*poverty level), between (*poverty level and 125% of poverty), or more than (*125%)?

To understand how well our programs fit people's need for support with long-term care costs, we would like to get a general idea of the level of savings and assets older people have.

102. (Ask homeowners only) If your home were for sale, roughly how much do you think you could get for it? Do you think it would sell for less than \$80,000, 80,000-120,000 or more than 120,000?

103. (Ask of MARRIED respondents) If assets are defined as savings – such as certificates of deposit, stocks, bonds, pension values, IRAs, and the cash value of insurance policies, but NOT including the value of a home, do you think you and your spouse have more or less than \$25,000 in total combined assets?

103A. (If more) Would you say your and your spouse's total combined assets are \$50,000 or less, \$50,001 to 100,000, \$100,001 to \$175,000, or more than \$175,000?

103B. (If less) Would you say your and your spouse's total combined assets are \$3,000 or less, \$3001 to 6,000, or more than \$6,000?

104. (Ask of UNMARRIED/DIVORCED/WIDOWED respondents) If assets are defined as savings – such as certificates of deposit, stocks, bonds, pension values, IRAs, and the cash value of insurance policies, but NOT including the value of a home, do you think you have more or less than \$25,000 in total combined assets?

104A. (If more) Would you say your total assets are \$50,000 or less, 50,001 to 100,000, or more than 100,000?

104B. (If less) Would you say your total assets are \$2,000 or less, between \$2000 and 4,000, between \$4000 and 12,000, or more than 12,000?

END OF INTERVIEW